

ATTACHMENT AA
Parent Survey

Form Approved
OMB No. 0920-XXXX
Exp. Date xx/xx/20xx

PARENT SURVEY

Name of person administering survey _____

Date survey administered _____ (mm/dd/yyyy)

Project component (CHECK ONE) Phone survey component
In-person component

SURVEY SECTIONS

- A. DEVELOPMENT AND LEARNING
- B. GENERAL HEALTH
- C. MEDICAL ISSUES
- D. MOBILITY/FUNCTIONING
- E. NUTRITION AND PHYSICAL GROWTH
- F. FAMILY DEMOGRAPHICS

**OPENING STATEMENT, CONFIRMATION OF ELIGIBILITY, AND VERBAL
 CONSENT FOR SURVEY COMPONENT
 SKIP THIS SECTION FOR IN-PERSON COMPONENT**

Hello. My name is _____. I would like to thank you for your interest in this important project about spina bifida! Without families like yours volunteering, we would not be able to learn what it is like to grow up with spina bifida in the United States today. Your information is very valuable to us.

Before we continue, I just need to ask two questions to make sure that you are eligible for the study.

Is your child between 3 and 5 years old? YES NO

And has he or she been diagnosed with spina bifida or myelomeningocele?
YES NO

IF NO TO EITHER OF THESE QUESTIONS, SAY: We need to talk to parents whose child is between the ages of 3 and 5 and has spina bifida. You aren't eligible for the study at this time, but I do thank you for your interest and your time. Do you have any questions for me? (ANSWER QUESTIONS, IF ANY). Have a nice day. Goodbye.

IF YES, CONTINUE.

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We are designing a project to learn more about what it is like to grow up with spina bifida. The information we collect today will help us design the project and help us identify the best ways to collect information from families like yours. We will ask you questions about your child's development and learning, mobility and functioning, general health, nutrition and physical growth. There are some questions about possible medical concerns that your child may or may not have experienced. There are also some questions regarding you and your family. When we finish the survey, we will ask you for your consent to review your child's medical and early intervention records. We will send you two separate forms to authorize the release of the medical and early intervention records. If you would rather not let the project team review your child's records, that is fine. You can still participate in today's survey.

Before we continue, I'd like you to know that taking part in this research is voluntary. You may choose not to answer any questions you don't wish to answer, or end the interview at anytime without penalty. In appreciation for your time, we will send you \$25.00. The survey will take about 30-40 minutes.

May I begin the interview?

(Interviewer: Circle one response) YES NO

A. DEVELOPMENT AND LEARNING

REPLACE X WITH CHILD’S NAME

First, let’s start with a few basic questions about you and X.

A1. What is your relationship to X?

- Mother (biological, step, foster, adoptive).....1 SKIP A2
- Father (biological, step, foster, adoptive).....2 SKIP A2
- Sister (step, foster, half, adoptive).....3 SKIP A2
- Brother (step, foster, half, adoptive).....4 SKIP A2
- In-law of any type.....5 SKIP A2
- Aunt.....6 SKIP A2
- Uncle.....7 SKIP A2
- Grandparent.....8 SKIP A2
- Other family member.....9 SKIP A2
- Other non-relative.....10 SKIP A2
- Female guardian.....11 SKIP A2
- Male guardian.....12 SKIP A2
- Other, specify.....13
- Refused.....-1 SKIP A2

A2. Specify other relationship _____

A3. Is X male or female?

- Male..... 1
- Female.....2
- Refused.....-1

A4. How often do you and X live in the same household...

- All the time.....1 SKIP A5
- Sometimes, specify how often.....2
- Never.....3 SKIP A5
- Refused.....-1 SKIP A5

A5. Specify how often you and X live in the same household _____

A6. Now I will ask you some questions about **X**'s development, behaviors and learning. There are also some questions about early intervention services that **X** may have used. Do you have any concerns about **X**'s *cognitive development*? By cognitive development, I mean things such as **age-appropriate** thought processes and intellectual abilities, including attention, memory, academic and everyday knowledge, problem solving, imagination and creativity.

- Yes..... 1
- No..... 2 SKIP TO A8
- Don't know..... -2
- Refused..... -1

A7. How would you describe your concerns about **X**'s *cognitive development*?

- Minor concerns..... 1
- Moderate concerns..... 2
- Severe concerns..... 3
- Don't know..... -2
- Refused..... -1

A8. Do you have any concerns about **X**'s *emotional and social development*? By emotional and social development, I mean things such as **age-appropriate** self-understanding, ability to manage one's own feelings, knowledge about other people, interpersonal skills and friendships.

- Yes..... 1
- No..... 2 SKIP TO A10
- Don't know..... -2
- Refused..... -1

A9. How would you describe your concerns about **X**'s *emotional and social development*?

- Minor concerns..... 1
- Moderate concerns..... 2
- Severe concerns..... 3
- Don't know..... -2
- Refused..... -1

A10. Do you have any concerns about **X**'s *physical development*? By physical development, I mean things such as **age-appropriate** changes in body size, proportions, appearance and the functioning of various body systems.

- Yes 1
- No 2 SKIP TO A12
- Don't know..... -2

Refused-1

A11. How would you describe your concerns about X's *physical development*?

Minor concerns.....1
Moderate concerns.....2
Severe concerns.....3
Don't know.....-2
Refused-1

A12. Keeping in mind X's age, do you have any concerns about his/her *ability to learn*?

Yes1
No2 SKIP TO A14
Don't know.....-2
Refused-1

A13. How would you describe your concerns about X's *ability to learn*?

Minor concerns.....1
Moderate concerns.....2
Severe concerns.....3
Don't know.....-2
Refused.....-1

A14. Keeping in mind X's age, do you have any concerns about his/her *ability to concentrate*?

Yes.....1
No.....2 SKIP TO A16
Don't know.....-2
Refused.....-1

A15. How would you describe your concerns about X's *ability to concentrate*?

Minor concerns.....1
Moderate concerns.....2
Severe concerns.....3
Don't know.....-2
Refused.....-1

A16. For the next series of questions, I would like to compare X to children about the same age who do not have spina bifida.

Some children are fairly quiet and passive and it takes a lot to get them to react to things. Does this sound ...

- Very much like X.....1
- A little like X, or.....2
- Not like X.....3
- Don't know.....-2
- Refused.....-1

A17. Some children are good at paying attention to things and staying focused on what they are doing. Does this sound...

- Very much like X.....1
- A little like X, or.....2
- Not like X.....3
- Don't know.....-2
- Refused.....-1

A18. Some children like to do things on their own even if it's hard. Does this sound...

- Very much like X.....1
- A little like X, or.....2
- Not like X.....3
- Don't know.....-2
- Refused.....-1

A19. Some children are restless, fidget a lot, and have trouble sitting still. Does this sound...

- Very much like X.....1
- A little like X, or.....2
- Not like X.....3
- Don't know.....-2
- Refused.....-1

A20. Some children try to finish things, even if it takes a long time. Does this sound...

- Very much like X.....1
- A little like X, or.....2
- Not like X.....3

Don't know.....-2
 Refused.....-1

A21. Some children get easily involved in everyday things that go on at home, like playing with toys, or paying attention to conversations. Does this sound...

Very much like X.....1
 A little like X, or.....2
 Not like X.....3
 Don't know.....-2
 Refused.....-1

A22. Some children get very distracted by sights and sounds, and can't seem to screen them out very well. Does this sound...

Very much like X.....1
 A little like X, or.....2
 Not like X.....3
 Don't know.....-2
 Refused.....-1

A23. Some children are frequently anxious or depressed. Does this sound...

Very much like X.....1
 A little like X, or.....2
 Not like X.....3
 Don't know.....-2
 Refused.....-1

A24. Some children have a lot of trouble making or keeping friends. Does this sound...

Very much like X.....1
 A little like X, or.....2
 Not like X.....3
 Don't know.....-2
 Refused.....-1

A25. When some children are with other children their same age, they take turns and cooperate. Does this sound...

Very much like X.....1

A little like X, or.....	2
Not like X.....	3
Don't know.....	-2
Refused.....	-1

A26. Would you say that X...

Has No trouble playing with other children,.....	1
Has some trouble playing with other children, or.....	2
Has a lot of trouble playing with other children.....	3
Don't know.....	-2
Refused.....	-1

A27. Compared with other children about the same age, how would you describe the appropriateness of X's behavior? Would you say that his/her behavior...

Is typical and appropriate for his/her age,.....	1
Is mildly inappropriate,.....	2
Is moderately inappropriate, or.....	3
Is severely inappropriate?.....	4
Don't know.....	-2
Refused.....	-1

A28. Compared with other children about the same age, does X learn, think, and solve problems...

Better than other children his/her age,.....	1
As well as other children,.....	2
Slightly less well than other children, or.....	3
Much less well than other children.....	4
Don't know.....	-2
Refused.....	-1

A29. How often does X play with or interact with other children his/her age (do not count other family members)?

Daily.....	1	SKIP A30
Weekly.....	2	SKIP A30
Monthly.....	3	SKIP A30
Less than monthly	4	SKIP A30
Never.....	5	SKIP A30
Other, specify.....	6	
Don't know.....	-2	SKIP A30

Refused.....-1 SKIP A30

A30. Other specify_____

INTERVENTION SERVICES

A31. Did X ever receive services from a program called Early Intervention services (called Babies Can't Wait in Georgia)? Children receiving these services often have an Individualized Family Service Plan (IFSP)

- Yes.....1
No.....2 SKIP TO A41
Don't know.....-2
Refused.....-1

A32. What type/s of Early Intervention services did/does X receive?

READ OPTIONS AND CHECK ALL THAT APPLY

- Equipment devices and/or services.....1 SKIP A33
Audiology services.....2 SKIP A33
Family training, counseling, and home visits.....3 SKIP A33
Health services.....4 SKIP A33
Medical services only for
diagnostic or evaluation purposes.....5 SKIP A33
Occupational therapy.....6 SKIP A33
Physical therapy.....7 SKIP A33
Psychological services.....8 SKIP A33
Service coordination services.....9 SKIP A33
Social work services.....10 SKIP A33
Special instruction.....11 SKIP A33
Speech-language pathology.....12 SKIP A33
Transportation and related costs.....13 SKIP A33
Other, specify.....14
Don't know.....-2 SKIP A33
Refused.....-1 SKIP A33

A33. Other specify_____

A34. How old was X when he/she first started regularly getting Early Intervention services from a professional? _____

A35. _____ (years) _____ (months)

A36. How old was X when he/she stopped getting Early Intervention services from a professional? _____

IF STILL RECEIVING EARLY INTERVENTION SERVICES WRITE "NOT APPLICABLE"

A37. _____ (years) _____ (months)

A38. What was the reason/s X stopped receiving Early Intervention services?

CHECK ALL THAT APPLY

- Age (i.e., too old).....1 SKIP A39
- Completed the duration of services recommended.....2 SKIP A39
- You (i.e., parent) decided to stop using services.....3 SKIP A39
- Other, specify.....4
- Don't know.....-2 SKIP A39
- Refused.....-1 SKIP A39

A39. Other specify _____

A40. How would you rate the Early Intervention services that X received?

- Excellent..... 1
- Very Good.....2
- Good3
- Fair4
- Poor.....5
- Don't know.....-2
- Refused.....-1

A41. Is X currently or did he/she ever receive services from a program called Special Education services? Children receiving these services often have an Individualized Education Plan (IEP)

- Yes..... 1
- No.....2 SKIP TO A49
- Don't know.....-2
- Refused.....-1

A42. How old was X when he/she first started regularly getting Special Education services from a professional? _____

A43. _____ (years) _____ (months)

A44. How old was X when he/she stopped getting Special Education services from a professional? _____
IF STILL RECEIVING EARLY SPECIAL EDUCATION SERVICES WRITE "NOT APPLICABLE"

A45. _____ (years) _____ (months)

A46. What type of Special Education services does/did X receive?
READ OPTIONS AND CHECK ALL THAT APPLY

- Equipment devices and/or services.....1 SKIP A47
- Audiology.....2 SKIP A47
- Behavior support/counseling/psychology services.....3 SKIP A47
- Health services.....4 SKIP A47
- Medical services only for diagnostic or evaluation purposes.....5 SKIP A47
- Occupational therapy.....6 SKIP A47
- Physical therapy.....7 SKIP A47
- Psychological services.....8 SKIP A47
- Service coordination services.....9 SKIP A47
- Social work services.....10 SKIP A47
- Special instruction.....11 SKIP A47
- Speech-language pathology.....12 SKIP A47
- Transportation and related costs.....13 SKIP A47
- Other, specify.....14
- Don't know.....-2 SKIP A47
- Refused.....-1 SKIP A47

A47. Other specify _____

- A48. How would you rate the Special Education services that X receives/received?
- Excellent.....1
 - Very Good.....2
 - Good3
 - Fair4

Poor.....	5
Don't know.....	-2
Refused.....	-1

A49. Does X currently...

READ OPTIONS AND CHECK ALL THAT APPLY

Attend a preschool program in an elementary school.....	1
Attend an early childhood or preschool center, or nursery school.....	2
Attend a child care center.....	3
Receive home-based services.....	4
Attend another program, specify.....	5
Does not attend any center and does not receive any home-based services.....	6
Don't know.....	-2
Refused.....	-1

B. GENERAL HEALTH

Great! Let's switch gears. The next few questions will be about X's general health. There are also a few questions about your own health.

B1. Compared with other children about the same age as X, how would you rate X's physical health in the past month?

Excellent.....	1
Very Good.....	2
Good	3
Fair	4
Poor.....	5
Don't know.....	-2
Refused.....	-1

B2. Compared to other children about the same age as X, how would you rate X's mental and emotional health in the past month?

Excellent.....	1
Very Good.....	2
Good	3
Fair	4
Poor.....	5
Don't know.....	-2

- Refused.....-1
- B3. How would you rate your own physical health in the past month?
- Excellent.....1
- Very Good.....2
- Good3
- Fair4
- Poor.....5
- Don't know.....-2
- Refused.....-1
- B4. How would you rate your own mental and emotional health in the past month?
- Excellent.....1
- Very Good.....2
- Good3
- Fair4
- Poor.....5
- Don't know.....-2
- Refused.....-1
- B5. Some children complain about experiencing pain. Has **X** ever complained of pain?
- Yes.....1
- No.....2 SKIP TO C1
- Don't know.....-2
- Refused.....-1
- B6. How often would you say **X** complains of pain?
- Daily.....1
- A couple of times per week (2 times/week).....2
- A few times per week (3-6 times/week)3
- A couple of times per month.....4
- Don't know.....-2
- Refused.....-1
- B7. How long has **X** experienced the pain? Would you say...
- Less than a month.....1
- At least 1 month but less than 3 months.....2
- At least 3 months but less than 1 year or,3
- Greater than 1 year.....4

Don't know.....-2
 Refused.....-1

B8. During the past month, has X had a problem with pain that lasted more than 24 hours?

Yes.....1
 No.....2
 Don't know.....-2
 Refused.....-1

B9. In general, when X complains of pain has the pain been caused by a specific injury (e.g., because of a fall)?

Yes.....1
 No.....2
 Don't know.....-2
 Refused.....-1

B10. In general, does X feel more, less, or about the same amount of pain as other children?

More pain.....1
 About the same amount of pain.....2
 Less pain.....3
 Don't know.....-2
 Refused.....-1

B11. Regarding X's pain, which regions are generally affected?

READ OPTIONS AND CHECK ALL THAT APPLY

Head1 SKIP B12
 Neck.....2 SKIP B12
 Face/Teeth.....3 SKIP B12
 Shoulder.....4 SKIP B12
 Upper arm.....5 SKIP B12
 Mid arm.....6 SKIP B12
 Lower arm.....7 SKIP B12
 Hand.....8 SKIP B12
 Buttocks.....9 SKIP B12
 Upper leg.....10 SKIP B12
 Mid leg.....11 SKIP B12
 Lower leg.....12 SKIP B12

Foot.....	13	SKIP B12
Sternum.....	14	SKIP B12
Chest.....	15	SKIP B12
Abdomen	16	SKIP B12
Spine.....	17	SKIP B12
Other, specify.....	18	
Don't know.....	-2	SKIP B12
Refused.....	-1	SKIP B12

B12. Other specify _____

C. MEDICAL INFORMATION

Those were the questions I had about general health. Now I am interested in medical problems that X may have experienced. As you know, children with spina bifida may experience certain medical problems and need special care and treatments. The next series of questions are about such potential medical problems and the related care that may be required.

HEALTH CARE

C1. **During the past 12 months**, how many times did X see a doctor, nurse, or other health care professional to receive care or treatment *directly related to spina bifida*? Please do not include well visits or general physical exams. _____ times

C2. Where does X receive his/her *spina bifida related* medical care **most often**?

Private physician's office.....	1	SKIP C3
Emergency room.....	2	SKIP C3
Hospital outpatient department.....	3	SKIP C3
Clinic or health center (NOT multidisciplinary spina bifida clinic).....	4	SKIP C3
Multidisciplinary clinic specialized in spina bifida.....	5	SKIP C3
Some other place, specify.....	6	
X does not go to one specific place most often.....	7	SKIP C3
Don't know.....	-2	SKIP C3
Refused.....	-1	SKIP C3

C3. Some other place
specify_____

C4. During the past 12 months, would you say that X received all the *spina bifida related* care that he/she needed?

- Yes.....1 SKIP TO C7
- No.....2
- Don't know.....-2
- Refused.....-1

C5. Why did X Not get all the *spina bifida related* care that he/she needed?

CHECK ALL THAT APPLY

(READ RESPONSES ONLY IF NECESSARY)

- Cost too much.....1
- No insurance.....2
- Health plan problems.....3
- Can't find a doctor who accepts X's insurance.....4
- Not available in area/transport problems.....5
- Not convenient times/could Not get appointment.....6
- Doctor did not know how to treat or provide care.....7
- Dissatisfaction with doctor.....8
- Did not know where to go for treatment.....9
- Child refused to go.....10
- Could not get time off from work to go.....11
- Treatment is ongoing.....12
- No referral.....13
- Lack of resources at school/daycare.....14
- Other, specify.....15
- Don't know.....-2
- Refused.....-1

C6. Other
specify_____

C7. **During the past 12 months**, how many times did X see a doctor or nurse for *general preventive care*, such as a physical exam or a well-child check-up? Please do not include doctor/clinic visits specifically related to spina bifida (e.g., visits to a neurosurgeon or urologist)._____times

C8. Where does X receive his/her *general/preventive* medical care most often? (e.g., immunization, well-child check-ups)

- Private physician's office.....1 SKIP C9
- Emergency room.....2 SKIP C9
- Hospital outpatient department.....3 SKIP C9
- Clinic or health center
(NOT multidisciplinary spina bifida clinic).....4 SKIP C9
- Multidisciplinary clinic
specialized in spina bifida.....5 SKIP C9
- Some other place, specify.....6
- X does not go to one specific place most often.....7 SKIP C9
- Don't know.....-2 SKIP C9
- Refused.....-1 SKIP C9

C9. Some other place
specify_____

C10. Now I will ask some questions that have to do with neurosurgery and urology
What is X's level of lesion?

- Thoracic lesion.....1
- Mid-lumbar lesion.....2
- Low-lumbar lesion.....3
- Sacral lesion.....4
- Don't know.....-2
- Refused.....-1

NEUROSURGERY

C11. Most children with spina bifida have a shunt. Does X have a shunt?

- Yes.....1
- No.....2 SKIP TO C21
- Don't know.....-2
- Refused.....-1

C12. Have you ever suspected that there may be a problem with the shunt?

- Yes.....1
- No.....2 SKIP TO C15
- Don't know.....-2
- Refused.....-1

C13. What made you suspect that there may be a problem with X's shunt?

CHECK ALL THAT APPLY

- Complaints of headaches.....1 SKIP C14
- Difficulties eating.....2 SKIP C14
- Gagging3 SKIP C14
- Weak cry.....4 SKIP C14
- Fuzziness.....5 SKIP C14
- Arm weakness.....6 SKIP C14
- High pitched cry.....7 SKIP C14
- Noisy breathing.....8 SKIP C14
- Cyanosis (was turning blue).....9 SKIP C14
- Difficulties breathing.....10 SKIP C14
- Other, specify.....11
- Don't know.....-2 SKIP C14
- Refused.....-1 SKIP C14

C14. Other, specify_____

C15. Has the shunt ever been obstructed?

- Yes.....1
- No.....2 SKIP C16
- Don't know.....-2 SKIP C16
- Refused.....-1 SKIP C16

C16. How many times has this happened in X's life? _____time/s

C17. Has the shunt ever been infected?

- Yes.....1
- No.....2 SKIP C18
- Don't know.....-2 SKIP C18
- Refused.....-1 SKIP C18

C18. How many times has this happened in X's life? _____time/s

C19. Has the shunt ever been replaced or changed?

- Yes.....1
- No.....2 SKIP C20
- Don't know.....-2 SKIP C20

Refused.....-1 SKIP C20

C20. How many times has this happened in X's life? _____time/s

C21. Has X ever received a diagnosis of tethered cord?

- Yes.....1
- No.....2
- Don't know.....-2
- Refused.....-1

C22. How many times has this happened in X's life? _____time/s

UROLOGY

C23. Has X ever had a urinary tract infection that was diagnosed by a doctor or health care provider?

- Yes.....1
- No.....2 SKIP C24
- Don't know.....-2 SKIP C24
- Refused.....-1 SKIP C24

C24. How many urinary tract infections would you say X has had? _____

C25. Has X been potty trained?

- Yes.....1
- No.....2
- X is currently being potty-trained.....3
- Don't know.....-2
- Refused.....-1

C26. Does X have accidental urinary leakage (i.e., incontinence)?

- Yes, during the day.....1
- No.....2 SKIP TO C29
- Yes, both during the day and night.....3
- Yes, but only at night.....4
- Don't know.....-2
- Refused.....-1

C27. How often does X have accidental urinary leakage (i.e., incontinence)?

- Daily.....1
- A couple of times per week (2 times/week).....2

- A few times per week (3-6 times/week)3
- A couple of times per month.....4
- Don't know.....-2
- Refused.....-1

C28. Would you say that X's accidental urinary leakage is a great problem, somewhat of a problem, or not a problem at all?

- A great problem.....1
- Somewhat of a problem.....2
- Not a problem at all.....3
- Don't know.....-2
- Refused.....-1

C29. Does X use some type of bladder management program?

- Yes.....1
- No.....2
- Don't know.....-2
- Refused.....-1

SKIP TO C33

C30. What type of bladder management program is X using?

CHECK ALL THAT APPLY
(READ RESPONSES ONLY IF NECESSARY)

- Clean Intermittent Catheterization (CIC).....1
- Dribble (wearing diaper).....2
- Crede (applying pressure to the abdomen).....3
- Indwelling catheter (tube in bladder all the time).....4
- Other, specify what type.....5
- Don't know.....-2
- Refused.....-1

C31. Does X use diapers or a pad?

- Yes, during the day.....1
- No.....2
- Yes, both during day and night.....3
- Yes, during the night.....4
- Don't know.....-2
- Refused.....-1

C32. How old was X when he/she started a bladder management program?
_____ years _____ months

C33. Did you, or anybody in your family, ever receive training or information about continence training or bladder management?

- Yes..... 1
- No..... 2 SKIP TO C35
- Don't know..... -2
- Refused..... -1

C34. How satisfied are you with the training you received on continence training or bladder management?

- Very satisfied..... 1
- Somewhat satisfied..... 2
- Not very satisfied 3
- Not satisfied at all..... 4
- Don't know..... -2
- Refused..... -1

C35. Does X have bowel accidents?

- Yes..... 1
- No..... 2 SKIP TO C41
- Don't know..... -2
- Refused..... -1

C37. How often does X have bowel accidents?

- Daily..... 1
- A couple of times per week (2 times/week)..... 2
- A few times per week (3-6 times/week) 3
- A couple of times per month..... 4
- Don't know..... -2
- Refused..... -1

C38. Would you say that X's bowel accidents are a great problem, somewhat of a problem, or not a problem at all?

- A great problem..... 1
- Somewhat of a problem..... 2
- Not a problem at all..... 3

Don't know.....-2
 Refused.....-1

C39. Does **X** have a bowel management program?

Yes.....1
 No.....2 SKIP TO C42
 Don't know.....-2
 Refused.....-1

C40. What type of bowel management program is **X** using?

Involuntary, uses diaper or pad.....1 SKIP C41
 Regular scheduled bowel
 movements with aids (enemas, digital stimulation).....2 SKIP C41
 Regular scheduled bowel
 movements with no aids used.....3 SKIPC41
 Other, specify.....
 Don't know.....-2 SKIP C41
 Refused.....-1 SKIP C41

C41. Other
 specify _____

C42. Did you, or anybody in your family, ever receive any training and information about bowel management?

Yes.....1
 No.....2 SKIP TO C
 Don't know.....-2
 Refused.....-1

C43. How satisfied are you with the training you received on bowel management?

Very satisfied.....1
 Somewhat satisfied.....2
 Not very satisfied3
 Not satisfied at all.....4
 Don't know.....-2
 Refused.....-1

SURGERY

Now I have a few questions about surgeries **X** might have had.

C44. How many surgeries has X had in his/her life? This includes, for example, the closure of the lesion or the insertion of a shunt. _____

C45. How many surgeries did X have in the past 12 months? _____

C46. Please tell me the year and what type of surgery X has had (e.g., 2007, shunt revision; 2005 cord release/untethering; 2004 Chiari decompression). If you are Not sure about the name of the surgery please describe what was done (e.g., spine surgery, brain surgery).

1. Date _____
Type of surgery _____
2. Date _____
Type of surgery _____
3. Date _____
Type of surgery _____
4. Date _____
Type of surgery _____
5. Date _____
Type of surgery _____

OTHER

C47. Does X have a diagnosis of something else? For instance, has a doctor or nurse ever told you that X has or have had any of the following?

READ RESPONSES AND CHECK ALL THAT APPLY

- Hearing problem.....1
- Vision problem.....2
- Asthma.....3
- Attention Deficit Disorder or
Attention Deficit Hyperactive
Disorder (ADD or ADHD).....4
- Latex allergy.....5
- Epilepsy or seizure disorder.....6
- Behavioral problem.....7
- Developmental delay.....8
- Ocular disorders (e.g., strabismus).....9
- Clubfoot.....10
- Foot/ankle deformities.....11
- Scoliosis (i.e., side-to-side curvature of the spine).....12
- Kyphosis (i.e., abnormally rounded back).....13
- Mental retardation or an intellectual disability.....14

Pressure sore.....15
 Don't know.....-2
 Refused.....-1

C48. Has a doctor or nurse said that X has or have had something else that was Not included in the list?

Yes.....1
 No.....2 SKIP TO D1
 Don't know.....-2
 Refused.....-1

C49. What was it that the doctor or nurse told you that X had?

D. MOBILITY/FUNCTIONING/INDEPENDENCE

MOBILITY

Now I would like to know how X gets around and what, if any, equipment he/she uses.

D1. Is X able to walk without any mobility problems and without using any mobility equipment at all?

Yes.....1 SKIP TO D9
 No.....2
 Don't know.....-2
 Refused.....-1

D2. Is X a *community ambulator*? That means that he/she is able to walk indoors and outdoors for most activities, but *may* need braces, crutches, or both. He/she may use a wheelchair for long distances or durations.

Yes.....1 SKIP TO D7
 No.....2
 Don't know.....-2
 Refused.....-1

D3. Is **X** a *household ambulator*? That means that he/she is able to walk only indoors and with apparatus. He/she is able to get in and out of a chair and bed with little if any assistance. He/she may use a wheel chair for some indoor activities at home or at daycare/pre school, and for all activities in the community.

- Yes.....1 SKIP TO D7
- No.....2
- Don't know.....-2
- Refused.....-1

D4. Is **X** an *exercise/emergency ambulator*? That means that he/she can only take a few steps. Walking is a therapy session at home or in the hospital. A wheelchair is needed to move from place to place.

- Yes.....1 SKIP TO D6
- No.....2
- Don't know.....-2
- Refused.....-1

D5. Is **X** a *Nonambulator*? That means that X uses a wheel chair for mobility. He/she may be able to transfer from bed to chair, but do no walking.

- Yes.....1
- No.....2
- Don't know.....-2
- Refused.....-1

D6. If **X** is Not walking, at what age did he/she stop walking?

_____years _____months **X** never walked.....76

D7. What equipment does **X** use to help with his/her mobility?

READ RESPONSES AND CHECK ALL THAT APPLY

- Walking aids (such as canes, crutches, and walkers).....1 SKIP D8
- Leg Braces (such as ankle-foot-orthosis, knee-ankle-foot orthosis, hip-knee-ankle-foot orthosis).....2 SKIP D8
- Manual wheelchair propelled by self.....3 SKIP D8
- Manual wheelchair propelled by other.....4 SKIP D8
- Electric wheelchair.....5 SKIP D8
- Other, specify.....6
- None of the above.....7 SKIP D8
- Don't know.....-2 SKIP D8
- Refused.....-1 SKIP D8

D8. Other
specify_____

D9. Have you moved or made any changes to your house or apartment to make it easier for X to get around at home?

- Yes.....1
- No.....2 SKIP TO D12
- Don't know.....-2
- Refused.....-1

D10. What kind of changes have you made to make it easier for X to get around?
CHECK ALL THAT APPLY

- Moved to a different house or apartment
(e.g., moved to an apartment on the first
floor or a single floor house).....1 SKIP D11
- Installed ramps/lifts.....2 SKIP D11
- Installed elevator.....3 SKIP D11
- Improved access to different rooms
(e.g., made the door to the bathroom wider).....4 SKIP D11
- Other, specify.....5
- None of the above.....6 SKIP D11
- Don't know.....-2 SKIPD11
- Refused.....-1 SKIPD11

D11. Other
specify_____

D12. How much does living with spina bifida affect X's ability to do the things that other kids do? Would you say a great deal, some, very little, or not at all?

- A great deal.....1
- Some.....2
- Very little.....3
- Not at all.....4
- Don't know.....-2
- Refused.....-1

D13. Has X ever received physical therapy?

- Yes.....1
- No.....2 SKIP TO D18
- Don't know.....-2

Refused.....-1

D14. How long has X received physical therapy?

_____years_____months

D15. Why does/did X receive physical therapy?_____

D16. How many times per week does/did X receive physical therapy?_____

D17. How long does/did each session last?_____

D18. Has X ever received occupational therapy?

Yes.....1

No.....2 SKIP TO D23

Don't know.....-2

Refused.....-1

D19. How long has X received occupational therapy?

_____years_____months

D20. Why does/did X receive occupational therapy?_____

D21. How many times per week does/did X receive occupational therapy?_____

D22. How long does/did each session last?_____

INDEPENDENCE

Now I will ask some questions about independence. I know that **X** is very young and may not be expected to perform all of the following types of activities independently yet. But I am interested in how independent **X** currently is in performing these types of activities

D23. Many people living with spina bifida “cath” (i.e., use clean intermittent catheterization) to empty their bladder. Is **X** cathing?

- Yes.....1
- No.....2 SKIP TO D28
- Don’t know.....-2
- Refused.....-1

D24. How independent is **X** currently at cathing?

- Independent without prompting.....1
- Independent with prompting.....2 SKIP TO D26
- Independent with prompting and supervision.....3 SKIP TO D26
- Dependent on adult but helps some.....4 SKIP TO D26
- Dependent on adult.....5 SKIP TO D26
- Don’t know.....-2 SKIP TO D26
- Refused.....-1 SKIP TO D26

D25. At what age did **X** manage his/her cathing schedule without being prompted by another person? _____ years _____ months

D26. What types of prompts does **X** use to remember to cath?

- Parental or adult prompt1 SKIP D27
- Beeper2 SKIP D27
- Alarm clock3 SKIP D27
- Other, specify.....4
- Don’t know.....-2 SKIP D27
- Refused-1 SKIP D27

D27. Other specify

D28. How independent is **X** in managing his/her bowel management program without prompting?

- Independent without prompting.....1
- Independent with prompting.....2 SKIP TO D30
- Independent with prompting
and supervision.....3 SKIP TO D30

- Dependent on adult but helps some.....4 SKIP TO D30
- Dependent on adult5 SKIP TO D30
- Does not have a bowel management program.....6
- Don't know.....-2 SKIP TO D30
- Refused-1 SKIP TO D30

D29. At what age did X manage his/her bowel program schedule without being prompted by another person? _____years _____months ____Does Not Apply

D30. What types of prompts does X use?

CHECK ALL THAT APPLY

- Parental or adult prompt.....1 SKIP D31
- Beeper.....2 SKIP D31
- Alarm clock3 SKIP D31
- Other, specify.....4
- None of the above.....5 SKIP D31
- Don't know.....-2 SKIP D31
- Refused-1 SKIPD31

D31. Other specify_____

D32. Is X, or somebody else, regularly inspecting X's skin?

- Yes.....1
- No.....2 SKIP TO D34
- Don't know.....-2
- Refused.....-1

D33. How independent is X in inspecting his/her skin?

- Independent without prompting.....1
- Independent with prompting.....2
- Independent with prompting and supervision.....3
- Dependent on adult but helps some.....4
- Dependent on adult.....5
- Don't know.....-2
- Refused.....-1

D34. How important do you think it is that X is or becomes independent at cathing, managing his/her bowel, and inspecting his/hers skin?

- Very important.....1
- Somewhat important.....2
- Not very important.....3
- Not important at all.....4
- Don't know.....-2
- Refused.....-1

D35. Do you think that **X** will become completely independent at managing his/her bowel and bladder, and inspecting his/her skin?

- Yes.....1
- Probably.....2
- No.....3 SKIP TO E1
- Don't know.....-2
- Refused.....-1

D36. At what age do you expect **X** to be independently:

Cathing or managing his/her bladder _____ years _____ months
 Managing his/her bowels _____ years _____ months
 Inspecting his/her skin _____ years _____ months

E. PHYSICAL ACTIVITY, NUTRITION, & WEIGHT

PHYSICAL ACTIVITY

The next few questions are about physical activity

E1. During the past 7 days, on how many days was **X** physically active for a total of *at least 60 minutes per day*? (Add up all the time that **X** spent in any kind of physical activity that increased his/her heart rate and made him/her breathe hard some of the time).

- 0 days0
- 1 day1 SKIP TO E3
- 2 days.....2 SKIP TO E3
- 3 days.....3 SKIP TO E3
- 4 days.....4 SKIP TO E3
- 5 days.....5 SKIP TO E3
- 6 days.....6 SKIP TO E3

7 days.....7 SKIP TO E3
 Don't know.....-2
 Refused.....-1

E2. What was the main reason that **X did not** participate in physical activities **in the past 7 days**? _____

E3. What types of physical activities does **X** generally participate in? Please list them starting with the activity he/she participates in most often.

1. _____
2. _____
3. _____
4. _____
5. _____

Don't know-2
 Refused-1

E4. Compared to most children **X's** age, would you say that **X** is

More active than other children 1
 About as active as other children.....2
 Less active than other children.....3
 Don't know..... -2
 Refused-1

E5. **During the past 7 days**, on how many days were *you* physically active for a total of *at least 30 minutes per day*? (Add up all the time that you spent in any kind of physical activity that increased your heart rate and made you breathe hard some of the time)

0 days0
 1 day 1
 2 days.....2
 3 days.....3
 4 days.....4
 5 days.....5
 6 days.....6
 7 days.....7
 Don't know.....-2
 Refused.....-1

- E6. How important do *you* feel that physical activity is?
- Very important.....1
 - Somewhat important.....2
 - Not very important.....3
 - Not important at all.....4
 - Don't know.....-2
 - Refused.....-1

- E7. On an average day, how many hours does **X** watch TV or DVD?
- X does not watch TV or DVD.....1
 - Less than 1 hr per day.....2
 - 1 hr per day.....3
 - 2 hrs per day.....4
 - 3 hrs per day.....5
 - 4 hrs per day.....6
 - 5 or more hrs per day.....7
 - Don't know.....-2
 - Refused.....-1

- E8. On an average day, how many hrs does **X** play video or computer games or use a computer?
- X does not use the computer or play video games.....1
 - Less than 1 hr per day.....2
 - 1 hr per day.....3
 - 2 hrs per day.....4
 - 3 hrs per day.....5
 - 4 hrs per day.....6
 - 5 or more hrs per day.....7
 - Don't know.....-2
 - Refused.....-1

NUTRITION

Now I will ask some questions about what **X** ate in the past week. I know it can be hard to remember but please do your best.

- E9. **During the past 7 days**, how many times did **X** drink *100% fruit juices* such as orange juice, apple juice, or grape juice? (Do **NOT** count punch, Kool-Aid, sports drink, or other fruit-flavored drinks)

X did not drink 100% fruit	
juices during the past 7 days.....	1
7-13 times.....	2
14 to 20 times.....	3
21-27 times.....	4
28 or more times in the past 7 days.....	5
Don't know.....	-2
Refused.....	-1

E10. During the past 7 days, how many times did X eat *fruit*? (Do **NOT count fruit juices)**

X did not eat fruits in the past 7 days.....	1
7-13 times.....	2
14 to 20 times.....	3
21-27 times.....	4
28 or more times in the past 7 days.....	5
Don't know.....	-2
Refused.....	-1

E11. During the past 7 days, how many times did X eat vegetables?

X did not eat vegetables in the past 7 days.....	1
7-13 times.....	2
14 to 20 times.....	3
21-27 times.....	4
28 or more times in the past 7 days.....	5
Don't know.....	-2
Refused.....	-1

E12. During the past 7 days, how many times did X drink a can, bottle, or glass of soda or pop, such as Coke, Pepsi, or Sprite? (Do **NOT include diet soda or diet pop)**

X did not drink soda in the past 7 days.....	1
7-13 times.....	2
14 to 20 times.....	3
21-27 times.....	4
28 or more times in the past 7 days.....	5
Don't know.....	-2

Refused.....-1

E13. **During the past 7 days**, how many glasses of milk did **X** drink? (Include the milk that X drank in a glass, or cup, from a carton, or with cereal)

- X did not drink milk during the past 7 days.....1
- 7-13 times.....2
- 14 to 20 times.....3
- 21-27 times.....4
- 28 or more times in the past 7 days.....5
- Don't know.....-2
- Refused.....-1

WEIGHT

Now I will ask you some questions regarding **X**'s weight

E14. How tall is **X** without his/her shoes on? _____ feet and inches or
_____ cms

E15. How did you determine **X**'s height?

- I gave my best estimate of **X**'s height.....1
- That's how tall **X** was when he/she was last measured...2
- Don't know-2
- Refused.....-1

E16. When was the last time **X**'s height was measured?

- Never.....1
- Less than a month ago.....2
- Between 1 month and 1 year ago.....3
- More than 1 year but less than 2 years ago.....4
- More than 2 years but less than 3 years ago.....5
- More than 3 years ago.....6
- Don't know-2
- Refused.....-1

E17. How much does **X** weigh without his/her shoes on? _____ lbs or
_____ kgs

E18. How did you determine what **X** weighs?

- I gave my best estimate of **X**'s weight

- (i.e., estimate NOT from a scale).....1
- That’s how much X weighed when
he/she was last weighed on a scale.....2
- Don’t know-2
- Refused.....-1

E19. When was the last time X was weighed on a scale?

- Never.....1
- Less than a month ago.....2
- Between 1 month and 1 year ago.....3
- More than 1 year but less than 2 years ago.....4
- More than 2 years but less than 3 years ago.....5
- More than 3 years ago.....6
- Don’t know-2
- Refused.....-1

E20. Have you ever been told by a healthcare professional that X is over or underweight?

- Yes, overweight.1
- No.....2 SKIP TO E23
- Yes, underweight.....3 SKIP TO E22
- Other, specify.....4
- Don’t know-2
- Refused.....-1

SKIP E21 IF CHILD WAS Not CONSIDERED OVERWEIGHT

E21. How old was X when you were told that he/she was overweight?
_____years _____months

SKIP E22 IF CHILD WAS Not CONSIDERED UNDERWEIGHT

E22. How old was X when you were told that he/she was underweight?
_____years _____months

E23. How would you describe X’s *current weight*?

- Very underweight.....1
- Slightly underweight.....2
- About the right weight.....3
- Slightly overweight.....4
- Very overweight.....5
- Don’t know-2

Refused.....-1

E24. How would you describe *your own* weight?

Very underweight.....1

Slightly underweight.....2

About the right weight.....3

Slightly overweight.....4

Very overweight.....5

Don't know-2

Refused.....-1

E25. Has X ever seen a professional nutritionist?

Yes.....1

No.....2

Don't know-2

Refused.....-1

F. DEMOGRAPHICS

We're almost done. To finish up, we have a few basic questions about you, X, and your family.

F1. What is X's date of birth? _____(mm/dd/yyyy)

F2. Where was X born? _____
City County State Country

F3. Is X Hispanic/Latino?

Yes.....1

No.....2

Don't know-2

Refused.....-1

F4. What is X's race/ethnicity?

CHECK ONE

White.....1

Black/African-American.....2

American Indian.....3

Alaska native.....4

Asian.....5

Native Hawaiian.....6

Pacific Islander.....	7
Other.....	8
Don't know	-2
Refused.....	-1

F5. Is X of Hispanic or Latino origin (Includes Mexican, Mexican American, Central American, South American, or Puerto Rican, Cuban, or other Spanish Caribbean)?

Yes.....	1
No.....	2
Don't know	-2
Refused.....	-1

F6. How many siblings does X have? _____

F7. How many people live in your household, including yourself? _____

F8. What is the primary language spoken in the household?

CHECK ONE

English.....	1
Spanish.....	2
Any other language.....	3
Don't know	-2
Refused.....	-1

F9. Is more than one language spoken in the household on a regular basis?

Yes.....	1
No.....	2
Don't know	-2
Refused.....	-1

F10. What is your current marital status?

CHECK ONE

Married (excluding separation).....	1
Living with a partner (cohabitating).....	2
Single, never married	3
Separated	4
Divorced	5
Widowed	6
Don't know	-2
Refused.....	-1

F11. What is your highest level of education?

CHECK ONE

- 8th grade or less..... 1
- 9th-12th grade; no diploma.....2
- High school grad or GED.....3
- Completed vocational, trade or business school program.....4
- Some college credit but No degree.....5
- Associate degree.....6
- Bachelor’s degree.....7
- Master’s degree.....8
- Doctorate or professional degree.....9
- Don’t know-2
- Refused-1

F12. What is your current employment status?

CHECK ONE

- Employed full-time..... 1 SKIP TO F13 OR F14
- Employed part-time.....2 SKIP TO F13 OR F14
- Not employed outside the home.....3
- Don’t know-2
- Refused-1

F13. You said that you are not currently employed outside the home. What is the main reason you are not currently employed? Is it because you are...

- A student.....1
- A homemaker.....2
- Able to work, but currently
Not working (for example, looking for a job).....3
- Permanently disabled.....4
- A full-time caregiver of X.....5
- A full-time caregiver of somebody other than X.....6
- Retired7
- Don’t know-2
- Refused-1

The next few questions are about **X**'s parents. Before I ask them, I need to know which parents live in this household with **X**.

IF RESPONDENT IS **X**'S MOTHER OR FATHER-GO TO F14

IF RESPONDENT IS SOMEBODY OTHER THAN **X**'S MOTHER OR FATHER- GO TO F15

F14. Earlier you mentioned that you are **X**'s mother/father. Are you **X**'s biological, adoptive, step, or foster mother/father? SKIP TO F17

- Biological mother..... 1
- Stepmother.....2
- Foster mother.....3
- Adoptive mother.....4
- Biological father.....5
- Stepfather.....6
- Foster father.....7
- Adoptive father.....8
- Don't know-2
- Refused-1

F15. Earlier you told me that you are **X**'s _____. Other than yourself, does **X** have any (other) parents, or people who act as his/her parents living here?

- Yes 1
- No2 SKIP TO F17
- Don't know-2
- Refused-1

F16. What is their relationship to **X**? CHECK ALL THAT APPLY. IF THE RESPONDENT RESPONDS "MOTHER" OR "FATHER" PROBE: 'IS THAT HIS/HER BIOLOGICAL, ADOPTIVE, STEP OR FOSTER'?

- Biological mother..... 1
- Stepmother.....2
- Foster mother.....3
- Adoptive mother.....4
- Biological father.....5
- Stepfather.....6
- Foster father.....7
- Adoptive father.....8
- Sister or brother (Step/foster/half/adoptive).....9
- In-law of any type.....10
- Aunt/uncle..... 11

Grandmother.....	12	
Grandfather.....	13	
Other family member.....	14	
Female guardian.....	15	
Male guardian.....	16	
Respondent’s partner or boy/girlfriend.....	17	
Other Non-relative.....	18	
Two or more of the same relationship type.....	19	
Mother type unknown.....	20	
Father type unknown.....	21	
Other relationship unknown.....	22	
Don’t know	-2	SKIP TO F17
Refused	-1	SKIP TO F17

F17. Enter relative or relatives _____
 ENTER THE NUMBER AND TYPE OF PERSON REPORTED. FOR EXAMPLE: “2 BROTHERS”. IF ONE OF THE RELATIVES IS ALREADY LISTED IN THE PICKLIST, DO NOT INCLUDE AGAIN HERE.

IF BIOLOGICAL MOTHER AND BIOLOGICAL FATHER LIVE IN THE HOUSEHOLD SKIP TO F19

F18. Does X have any other parents, or people who act as his/her parents, who do not live at this address?

Yes	1
No	2
Don’t know	-2
Refused	-1

F19. What is their relationship to X?

Biological mother.....	1
Stepmother.....	2
Foster mother.....	3
Adoptive mother.....	4
Biological father.....	5
Stepfather.....	6
Foster father.....	7
Adoptive father.....	8
Sister or brother (Step/foster/half/adoptive).....	9

In-law of any type.....	10
Aunt/uncle.....	11
Grandmother.....	12
Grandfather.....	13
Other family member.....	14
Female guardian.....	15
Male guardian.....	16
Respondent’s partner or boy/girlfriend.....	17
Other Non-relative.....	18
Two or more of the same relationship type.....	19
Mother type unknown.....	20
Father type unknown.....	21
Other relationship unknown.....	22
Don’t know	-2
Refused	-1

F20. We want to get a sense of what it costs families to get care for their children who are living with spina bifida. The next few questions are about costs, insurance and finances Does X have any type of health coverage, including health insurances, prepaid plans such as HMOs, or government plans such as Medicaid?

Yes.....	1
No.....	2
Don’t know	-2
Refused.....	-1

SKIP TO E22

F21. Is X insured by Medicaid or the State Children’s Health Insurance Program S-CHIP? In this state, the program is sometimes called PeachCare?

Yes.....	1
No.....	2
Don’t know	-2
Refused.....	-1

F22. Does X have more than one type of insurance coverage?

Yes.....	1
No.....	2
Don’t know	-2
Refused.....	-1

F23. Who pays for X’s **spina bifida related** care and treatments?

- X's insurance pays for all spina bifida related care and treatments1 SKIP TO F24
- X's insurance pats for some of X's spina bifida related care & treatment.....2
- X's insurance pays for none of X's spina bifida related care & treatment.....3
- Don't know-2
- Refused.....-1

F24. On average, how much do you estimate that you pay for **X's spina bifida related** care and treatments *per month* (i.e., NOT covered by insurance, do not include co-pay)?

\$ _____

F25. Have you ever tried to get your insurance or health plan to pay for any **spina bifida related** care or treatments for **X** but they wouldn't pay?

NOTE: THIS DOES NOT INCLUDE DEDUCTIBLES THAT ARE A REGULAR FEATURE OF THE INSURANCE POLICY OR PLAN

- Yes.....1
- No.....2 SKIP TO F26
- Don't know-2
- Refused.....-1

F26. Which of the following items would your insurance NOT pay for? (What wouldn't your insurance pay for?)

CHECK ALL THAT APPLY

- Diagnostic procedures or tests.....1
- Surgery.....2
- Special equipment.....3
- Therapy services.....4
- Prescriptions/medications.....5
- Other, specify.....6
- Don't know.....-2
- Refused.....-1

F27. What is your family's total income? This includes income from all sources such as wages, salaries, unemployment payments, public assistance, social security, retirement benefits, help from relatives etc. Please report amount **before** taxes.

- <\$10,000.....1
- \$10,000-19,999.....2

\$20,000-29,999.....	3
\$30,000-39,999.....	4
\$40,000-49,999.....	5
\$50,000-59,000.....	6
\$60,000-69,999.....	7
\$70,000-79,999.....	8
\$80,000-89,999.....	9
\$90,000-99,999.....	10
More than \$100,000.....	11
Other, specify.....	12
Don't know	-2
Refused.....	-1

F28. Does your family receive any of the following?

CHECK ALL THAT APPLY

Food stamps or food vouchers.....	1
Supplemental Security Income (SSI).....	2
Free or reduced cost school lunches.....	3
Women, Infants and Children Program (WIC).....	4
Don't know	-2
Refused.....	-1

F29. Has your family experienced financial problems in order to pay for X's SB related care and treatments?

Yes.....	1
No.....	2
Don't know	-2
Refused.....	-1

F30. We would love to hear what you thought of the survey. Please tell us what you think _____

That was the last question on the survey. Thank you once more for participating.

Please verify your address and phone number so that we can mail your check.

Street	City	State	Zip Code
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Home Telephone Number	Cell Phone Number
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What other person could we contact to get in touch with you if we cannot reach you at your address or phone number?

First Name	Last Name	Relation	Phone Number
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FOR SURVEY COMPONENT: We will mail you \$25.00 for participating within the next week.