

Thank you for agreeing to participate in our study.

Please fill out pages 1-6 and have your parents fill out page 7, 8

Please return this via mail (4 Benjamin Green Lane, Mahopac, NY 10541) or fax (914 248 9658)

Background Information

B1. I am _____ years old.

B2. I am male / female

B3. What disability/disorder does your sibling with special needs have? _____

B4. How old is your sibling with special needs _____

B5. Do you share a bedroom with your sibling with special needs? Yes / No

B6. Do you have any other siblings that live at home? Yes/No If "Yes", then how old are they?

B7. Do both of your parents live with you? Yes / No

If not, please explain. _____

B8. Does your sibling with special needs live with you full time? Yes / No (Circle One)

If not, please explain. _____

B9. Have you been to a special needs "sibling support" group meeting? Yes / No (Circle One)

If so, (approximately) how many times? _____

B10. Which word best describes how you feel about your sibling with special needs most of the time? (Circle all that apply.)

Angry Frustrated Loving Understanding Neutral Confused Jealous Guilty Afraid

B11. I was _____ years old when I realized that my sibling with special needs was "different?"

B12. My parents have discussed with me who will be responsible for my sibling with special needs when they are no longer able to take care of them. Yes / No

Please circle the NUMBER that matches the level to which you agree or disagree with each item on the proceeding pages.

Questions about my Sibling with Special Needs

S1. I consider myself educated on my sibling's disability.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>	<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

S 1a. Parents / Doctors / Teachers / Reading (Circle One) have provided me with this education.

Other _____

S2. I understand the limitations my sibling has as a result of their disability.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>	<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

S3. I have a close relationship/friendship with my sibling with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>	<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

S4. I am the person my sibling with special needs is most likely to express their feelings to.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>	<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

S5. I feel responsible for protecting/keeping my sibling with special needs safe from harm.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>	<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

S6. I feel responsible for taking care of my sibling with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>	<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

S7. I should be responsible for my sibling with special needs when my parents can't.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>	<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

S8. I feel comfortable telling friends about my sibling with special needs and their disorder.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>	<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

S9. I feel comfortable telling a potential boyfriend/girlfriend about my sibling and their disorder.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

S10. My parents pay more attention to my sibling with special needs than they do to me.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

S11. Our family plans are disrupted because I have sibling with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

S12. I have more responsibilities at home (because of my sibling with special needs) than most of my friends.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

S13. My parents encourage me to do activities without my sibling with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

S14. My parents don't have enough time to spend with me because they focus on my sibling with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

S15. My parents make an effort to help me handle my sibling's disability.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

S16. I feel that I have responsibilities to supervise and care for my sibling with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

S17. My parents pay more attention to me than my sibling with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

Please continue on the next page

Questions about Myself

M1. I would define myself as a very hard worker in school.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

M2. It is important to me to perform all tasks as perfectly as possible.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

M3. I am proud of my accomplishments in school.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

M4. My parents pressure me to be well-behaved at home.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

M5. I feel guilty if I am not well-behaved at home.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

M6. My parents pressure me to get good grades in school.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

M7. I feel guilty if I if do not get good grades in school.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

M8. I participate in extracurricular activities (sports, clubs, etc.).

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

M9. I feel that I am lucky to be able to participate in such activities.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

M10. My parents don't put any pressure on me to get good grades in school.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

Please continue on the next page

M11. My grades are usually closest to a... (Please circle one)

F D C B A

M12. What do you find most difficult about your sibling with special needs?

M13. How do you feel about people who don't understand special needs or developmental disorders?

M14. How do you feel about people who aren't sensitive to the fact that you have a sibling with special needs?

M15. How do you feel about bringing your sibling into a new situation where they have to interact with people they don't know?

Please continue on the next page

Questions about my Parents

P1. I have a close relationship with my parents.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>	<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

P2. I can talk to my parents about any problems I am having with my sibling with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>	<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

P3. I feel that my parents help me with school work and studying.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>	<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

P4. I feel that my parents appreciate my success in school.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>	<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

P5. I feel that my parents pay more attention to me when I do well in school.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>	<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

P6. I feel that I cannot talk to my parents about problems I am having with my sibling with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>	<i>(Slightly Agree)</i>		<i>(Agree)</i>		<i>(Strongly Agree)</i>

P7. Do you feel your parents' daily lives are different because of your sibling with special needs

Yes / No

If you answered "Yes" please explain how.

Please have your parents answer the questions on the next two pages (pg. 7, 8)

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Questions for the Parent of a Child with Special Needs

T1. I expect my typically developing child/children to become the primary guardian (in the future) for my child with special needs.

Yes No

T2. If so, I have discussed with my typically developing child the prospect of them becoming my child with special needs' primary guardian in the future.

Yes No

T3. My typically developing child supervises my child with special needs (circle one):

Never Once a week 2-3 times per week 4-6 times per week Every day

T4. I am more likely to: (Circle One)

A. Hire a "sitter" for my child with special needs, when needed.

B. Have my typically developing child be the "person in charge"

T5. What is your child with special needs' disability/disorder?

(Be as specific as you feel comfortable) _____

T6. I have more patience with my typically developing child than with my child with special needs.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

T7. I have more patience with my child with special needs than with my typically developing child.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

T8. I consider myself educated on my child with special needs' disability.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

T9. I spend more time with my child with special needs than with my typically developing child.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

T10. I considered myself adequately prepared for having a child with special needs before I had them.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

T11. I put more pressure on my typically developing child to meet my expectations for them.

1	2	3	4	5	6	7	8	9	10
<i>(Strongly Disagree)</i>		<i>(Disagree)</i>		<i>(Slightly Disagree)</i>		<i>(Slightly Agree)</i>		<i>(Agree)</i>	<i>(Strongly Agree)</i>

T12. Did you sit down with your typically developing child at some point to discuss the differences between them and their sibling with special needs? Yes / No

T13. How old were they when you first had "the conversation?" _____

T14. How did you explain the differences to your typically developing child?

T15. When you go out as a family, do you let your typically developing child choose the activity/place sometimes? (Regardless of what your child with special needs would like)

16. Is there anything else you would like to share with us regarding the dynamics of your family in relation to your child with special needs?

17. What state do you live in ? _____