

Report #6

Reflections from Adolescent Siblings who have a Brother or Sister with an Autism Spectrum Disorder

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Section I: Introduction

Although there has been some research on children who have a brother or sister with autism, there has been little written about how siblings feel during adolescence. Being a teenager can be difficult, and family relationships start to change. Therefore, we wanted to know how teenage siblings felt their childhood had been affected by having a brother or sister with autism. We also wanted to know what challenges adolescent siblings face, what kind of relationship they have with their brother or sister, and, basically, their points of view.

We were very happy when Dr. Gael Orsmond received a grant from the National Institutes of Health (NICHD) to recruit and involve adolescent siblings in our families already participating in our longitudinal study.

This report contains comments from almost 60 adolescent siblings who participated in the study. These siblings range in age from 12 to 18, and participated in a phone interview and completed a mailed survey. We are delighted to share with you some of what they shared with us. We have changed personal information to protect the identity of those participating in the study.

We thank the siblings who participated and shared their insights with us. You are helping us to learn about a unique living experience. We are grateful for the time that you gave to us.

Thank you!

Gael Orsmond
Marsha Mailick Seltzer
Marty Wyngaarden Krauss

Section II: Reflections from Siblings

How Siblings Describe their Relationships

She's great. I can hardly even tell she has a disability. She panics about stuff, but I love her. She's my sister and I wouldn't have it any other way.

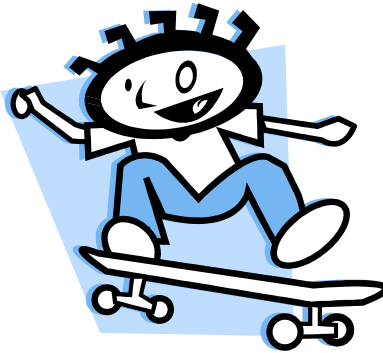
We get along as normal sibs do. We have our ups and downs. At times he can be a caring person but at other times it's harder to get along with him and he can be unreasonable.

She's pretty funny, but in a different way. Me and her will joke around. Sometimes she screams and hits and that's why...like I guess like normal brothers and sisters we'll end up in fights.

He's really nice I guess. He always gets upset and jealous when I'm with my friends. Usually we barely talk, but usually we get along.

He is an incredibly smart person. He's outgoing, loves to feel like he's part of a group. He doesn't like to be an outsider or different from everyone else. We get along pretty well. We don't argue that much. We will have disagreements, but it's a pretty good relationship.

She's my sister and I love her. I don't talk to her that much. We get along but she's very different from me so it's hard.



He's an all around great guy. He's friendly. Everyone at school loves him. We don't even think he has a problem - he's just one of us, you know? He's just my little brother.

She can be really nice. We used to be able to relate better when we were younger. Now she just goes to her room to watch TV.

He's non-verbal. We communicate by hugs. That's how we bond. If he does something I'm happy with, I'll give him a hug or a kiss.

Well, he can be annoying sometimes. Otherwise, he can be really interesting. It depends, sometimes we get along fine and sometimes we fight over the smallest things, like any siblings.

I think we get along well. Even if it's more difficult at times. Even as little kids we'd wrestle, go for walks together, do bike rides.

He's really kind and caring but can be self-centered at times.

Difficult, growing up with him. I learned not to judge people. He's a really nice kid, but he doesn't understand sometimes. Now that I'm gone at school we get along better. He calls me a lot.

We get along sometimes and sometimes we don't. The relationship is more on the positive side. We don't fight all the time.

I think that even though he's handicapped, he knows that I love him and he's just like a normal brother.

She gets along with me better now that I'm older. I'm bigger than her and she likes bigger people to lean on.

He's a really laid back guy. Very quiet, cooperative with whatever we want to do. A very pleasant guy to be around. That's it I guess.

He's a good brother. Likes to talk. Likes school and football. Won't ever say anything bad about you. Doesn't pick on anyone and he's always nice. We get along good. We don't fight that much at all.

Since he's gotten older we hang out more. He's good tempered around me. Better than with my mom actually.

He's a very sweet person. Very caring towards everyone. For the most part, we get along pretty well. There are times we fight, but it's more me though, he might do something that makes me upset. Sometimes it's almost like he's nervous around me.

Being autistic, she isn't restrained by societal issues. It's different to have someone around that's not affected by culture and is simple, well in a way she is.

We don't really get along. We kind of coexist. Doesn't seem to realize that I 'm there, doesn't care. Most of the time he is in his own world, isolated. He is distant with most people except my mother. It is strange that an older brother doesn't teach you things, like to write letters, show things. It's the other way around like I teach him to tie shoes.

She is very affectionate to me not in words. When she feels lonely she will come into my room, grab my hand, physical affection not verbal. I would say she's sweet, cute. It's hard to tell her emotions, just feel what I can see.

I have to be careful of what I say so he doesn't take it the wrong way.

Out of anyone in our family we get along the best. The two of us grew up together, we were first together. He always tries to have me feel better when I am upset. He comes to me when he is upset or had a bad day. He likes to talk to me about his problems. The most friendly and social person I know. He is the first to apologize. The kindest person I know. We rarely fight, if we do it is solved in a few minutes.

She likes to be around me, she is always happy around me, she likes to play with me. She pushes me around a lot, probably because she knows I am her younger sister so she knows she can boss me around.

We usually get along pretty well and have the same interests. We fight occasionally like all siblings. I consider him to be my best friend. He is more open than I am, our personalities are different but we still get along pretty well.

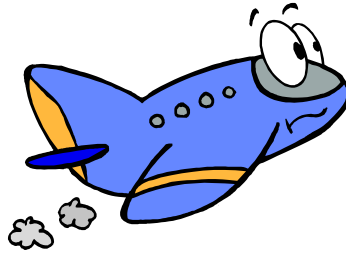
When we were younger we didn't get along well, we had sibling fights. Once I got older I could relate to him better. He doesn't have friends, only the family. I try to be nice to him but sometimes I am in a bad mood. We get along better than what we used to.

He has to be one of the nicest people I know. Very pure, loving kid, always very positive, optimistic. Our relationship has been basically good. When I was younger, I felt the regular sib rivalry. I felt resentment towards him (Why can't you be normal?) and then our relationship improved over the years. As I grew older I learned to appreciate him and learned that it is not his fault.

I have two roles-parent and brother. I have the brother relationship with him so when he's in a good mood we can hang out. I have the parent relationship when he's in a bad mood. If he's in a good mood he's one person, if he's in a bad mood he's someone else.

To me he is the most caring and innocent boy. I love him to death. Our relationship has grown apart since I moved to college. It was stronger when I was 13 and 14.





Frustrations and Worries

It's annoying that she tries to get attention from hitting. Cries about things that don't make a difference - how soon we're having dinner, etc.

She takes a long time to adjust to changing circumstances. Gets mad if you criticize her. Throws a fit.

He's very compulsive about things. If I bring the cordless phone to my room, he'll put it back. There's been phases that he'll do things that annoy me.

The worst time was when he was prone to violent rage attacks. But I know he didn't mean to do the things he did.

She has problems controlling herself. She displays emotions aggressively by pulling hair and hitting (especially when I'm around). I'm younger so we've spent a lot of time together. You can tell that we do love each other but we also can fight at times too. Sometimes she can have a lot of anger towards me, but all in all we do love one another.

As he got older he got more violent and stuck into a rut. If something didn't go as planned, he got violent until we couldn't do anything about it-throwing fits on holidays. As we got older, he wouldn't want me to do stuff with him. Only dad and mom or he gets upset.

Sometimes she can get really ornery. Starts to hit sometimes but me and my brother can usually stop her.

He has some mood swings if he doesn't get a lot of sleep. Changes in medicine will do it too. Sometimes you have to just let him have his way when he's mad.

Quite annoying when she keeps on asking you questions.

My parents would get into fights about how to take care of him. I would be angry about him and blame him for this.

I always worry about what's going to happen to her later in life. I'm hoping she will get better even though I know the chance of that is small.

I worry that she might hit too many people or hit the wrong person.

I worry about his weight, his self control.

I worry that he doesn't realize his limitations. He wants to do things without knowing what's involved in doing them.

I guess my major worry is that he'll end up in some place where they won't take care of him.

I don't want him to get hurt or be alone his whole life.

She's quite vulnerable.

I worry that she can't tell us sometimes why she's unhappy and I'm also worried about her seizures.

I worry that he will always be how he is now and won't progress and get better. But I'm pretty sure that won't happen.

Sometimes I worry...I want our relationship to be closer. I worry that it's hard to do-to build on our relationship.

I am worried that he will run into the street and get hurt. He doesn't recognize danger and can get hurt.

I have lot of health related worries about her.

I am always worried he will get in trouble with the law or lose a lot of money.

He is so friendly and nice that I am worried that people will take advantage of him because of his generosity and kindness.

I worry that he might not be able to make it on his own when he moves out.

Family Relationships

She takes so much care and time. My mom is really busy with her. So I don't get to spend as much time as I'd like to with my mom.

Our [the family's] mutual regard for him makes us closer.

When I was younger I was mean to my sister. I hope I've gotten better. It's harder, my mom comes home late and she's stressed. My sister might put her over the edge and then she'd be more likely to get mad at me as well.

A lot of what I do with my mom is more valuable, because a lot of times being one on one with my mom is rare.

The entire family is affected. I'm still fairly close to my mother. My parents try to give me attention. There are some things I can't do because of having a brother with autism. My parents can't always give me a lot of time but they do the best with what they've got.

I'm a lot closer with my mom. Talking about my brother and how we understand him and how lucky he is to have us as a family.



My mom and I are close. She understands a lot, how to deal with situations so we join forces together to help one another out and also help my sister out. We have a really great relationship.

Technically I'm supposed to be the middle child but I act like the oldest. So sometimes my mom will give me a lot of the "oldest" responsibilities and sometimes she'll want me to act like the younger kid.

I'm kinda jealous of what he gets. [My family relationships have been] affected a tiny bit, but not to the point where it drives me crazy or anything.

He doesn't affect any real relationship in my family.

I have more respect for her [my mother].

[My relationship with my mother has been affected] in a positive and negative way. More positive. If I get frustrated with my brother, she [my mother] reminds me why I should be more understanding. Our relationship is probably closer because of him.

My mom and I, we're alike, stubborn, a lot of times for my sister's sake I'll give in to make it easier for my mom. Negative because it is not anyone's fault but my mom has to give time to my sister, not that I feel neglected. Sometimes I need my mom and she is busy with my sister. Kind of frustrating but not much I can do.

It makes me respect her [my mother] more from seeing how well my brother has turned out and how he does. It makes me look up to her more.



It's hard dealing with it [having a brother or sister with autism]. My other friends can watch baseball games and go out after school. I have to come home to watch my sister.

My sister takes a lot of her [my mother's] attention. So I don't get to talk and get the attention from my mother as I would.

When I was younger I had to be more independent because my mother had to spend time with him. I learned to be independent more than others.

Because we all have to participate in caring for him it gives the family more unity and togetherness.

I feel like I can relate to my dad about it because we were going through the same thing. I can talk to my dad a lot since my sister usually turns to my mom more.

My father does spend quite a bit of time with my brother. It draws away from some of the attention I get. But still, my father does the best he can for me.



We [father and daughter] have a difficult relationship. He [father] feels it's his fault she is this way (which isn't true). But he takes the blame. So he tries to keep her more happy. So it's been really hard.

She really likes to be daddy's little girl. If I'm talking with my dad, she will come over and push me out of the way. But we all get along.

If I want to talk to someone in the house, if Mom's dealing with her, the only other person to talk to is my dad.

[Having a family member with autism] taught us to join together as a family and overcome obstacles. It taught us to be there for one another and how to love and be strong for one another.

Our life was centered around making sure he got everything he wanted. He put so much strain on all of us. My mom and dad were living in fear.

[The impact on my family has been] mostly positive. It's weird thinking of our family without him in it. We're a stronger family because of him. He's really positive and it helps us keep in a positive mood. We're a lot happier because of him.

We don't go out in public. We don't do things together as a family. It's just hard to get her out in public without her getting upset or wild.

Sometimes she can be a handful, and put a lot of strain on the family. It gets us down and sad just because of the things she does, flipping out and we don't know why, makes us feel bad. Other times things can be great. When she's happy we're happy.

She's got bursts of energy and light that rubs off on everybody.

It's been hard but we grew closer than a regular family when dealing with him. We all have to work on it together.

It carved us like in different countries. My mom and dad are often at odds. It's divided us in some ways and brought us closer in other ways. Puts a lot more tension in the house.





Siblings' Feelings

He's given me great confidence.

Sometimes I feel kinda lonely. When she gets bent out of shape I feel like I can't do anything. My parents have to take care of her and I feel like there's nothing I can do.

If she's crying, I'm affected a lot. Like having someone add on more weight. It's harder, like lifting weights. My level of tolerance goes down.

If he's jealous then it doesn't make me happy.

Sometimes if I feel something's unfair between us, I can do more than she can. I am more grateful, appreciate what I can do. I realize that things are a lot harder for her.

I learn a lot from my brother. How to be a better person, because he'll remind me to be better, through his actions he cares about me and wants me to be a better person.

He makes me feel more privileged. Being able to read and write.

It opened my eyes as to how blessed I am to have my ability and skills. It's not taken for granted how I have been able to do what I can.

I can get more out of life and I appreciate that.

My views on people with disabilities have been more positive.

Sometimes I feel guilty if I get mad at him because he doesn't intend to hurt people. I feel bad if I yell at him.

Having him [around] teaches you patience with yourself. I learned to tell myself to try in different ways.

I consider myself lucky that I have the ability to communicate with others and have a normal life.

He tries so hard for things I take for granted. It puts me in my place. What I am like and am capable of doing . . . I appreciate what I have.

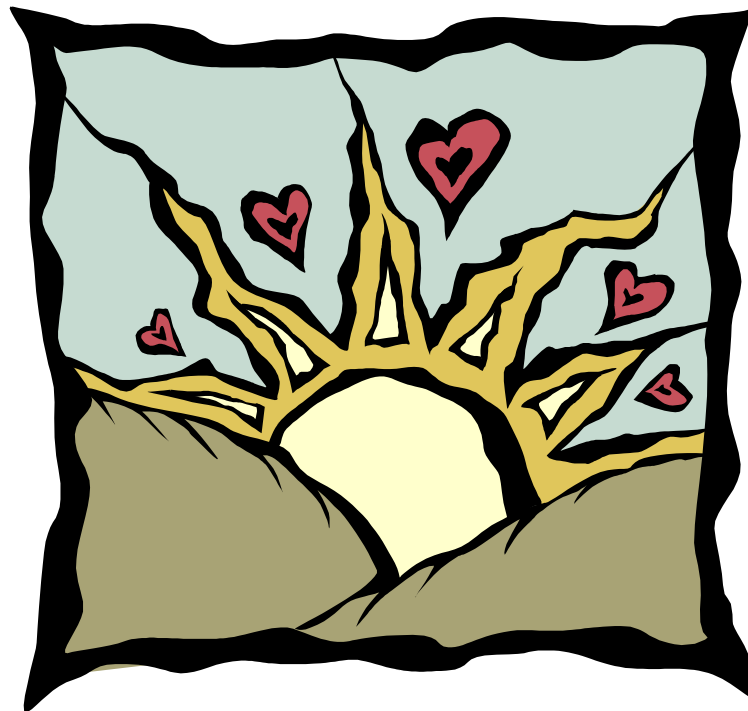
I had to learn to be more independent.

I realize that there are a lot of different people in the world. It taught me not to judge people without getting to know them.

I feel lucky that even though she has autism and I don't. I'm lucky I guess.

It puts more pressure on me to do well, more responsibility because the others have autism.

I have more compassion for people and understand more about what people go through. I have more sympathy for people, more patience.



Thoughts about the Future

I wonder how it's going to fit into the lifestyle I plan on leading when I grow up and have kids. I wonder if I'm going to be responsible for her?

Once my parents are not around I'll have to take care of her. That's a scary thought because if there's no one to take care of her it will have to go to me.

I won't be her direct caretaker but will oversee all that stuff.

I might have to live around [the area]. I won't have absolute freedom & will have to come back and check on him. I will have to oversee his care.

I enjoy helping him but my life has been filled with autism and disabilities already so I don't think I'd want to pursue a career in it.

I wonder what we're both going to do as adults. I'll probably be the one who is her legal guardian. I just wonder what that will be like.

I don't think he will affect my future. He can handle himself.

I'm sure I'll end up taking care of him when my mom and dad are really old. Unless he gets better, but that probably won't happen. It's not a bad thing, just different.

He'll probably need to live with one of us when we're older. I've never had a problem with that. He'll always be a big part of my life. Knowing him will make me a better person and he does have a big effect on my future.

I can rub it in people's faces that I have a smart brother. I don't see how he would affect my future.

It's going to be tough when my parents are not going to be here. She's so used to it. I think about it a lot, what I'm going to have to care for her. I know it's the far future but how it will affect my family, husband and children.

I worry about the future. I try not to think about it. When my parents are older, I wonder who is going to take care of her, when my parents are not here? It's scary to think this might happen.

She's going to be under my supervision. I plan to have kids when I get married. I have a boyfriend and he loves her to death, he takes care of her like his daughter, he takes her to movies. He's the one I plan to marry and he knows she's going to live with me.

I'm concerned sometimes since he wants to have a family but doesn't have the social skills for that.

I won't have contact with him. We'll go separate ways.

I wonder whether I'm going to have to care for him or he's going to care for himself. What's going to happen to him in the future? How involved I will be in his life?

What he's going to be able to do in his life. If he will get a job, find support, be able to understand people better. What will happen when my parents are gone?



What Siblings are Proud Of

That she has a lot of courage - always diving into things. She's handling her lifestyle the best she can.

When she can do stuff by herself.

He's achieved so much. He can communicate and has come a long way since he was younger. It's made me proud to be his brother and part of the family.

She's done well at her new job.

By conquering obstacles that I know are difficult for him at his level.

In ways, I've seen what he's gone through and how he deals with it. He's come a long way.

I watched him grow in stages of reading/writing. Once he read an entire book in an hour and I was so excited. Watching him grow as a person has made me proud. He has a job and gets there on time. Never complains, always happy go lucky.

I think he's starting to realize more about the world and what's out there.

Whenever I do something that's important to me, she'll go and tell her friends or people at school because she's proud of me. It makes me feel good.

The way she can really get people to open up around her. It's special, a nice talent.

By overcoming his disability a lot from how he used to be.

It's made me proud that he's started to speak more clearly. He's a good learner if I want to teach him something.

I feel good that he can do something good with his life. Makes me proud to be his brother.

She can do things that I can't. She's good with little kids which I never feel like I am.

Having him be my brother-it's a cool thing because it's not something everybody has.

He ignores things. We used to go to this neighborhood where people were mean to him and he would ignore them even though he was aware of it. I had to respond, I don't have that strength, I wish I did.

He's real good at sports so when he wins it makes me proud.

Because she's gone through a lot in her life. She's going through a lot. It makes me feel good that she does the things that she's done. She's had a hard life compared to other people.

As far as I remember when she was speechless and now you can sit with her and have a full blown conversation.

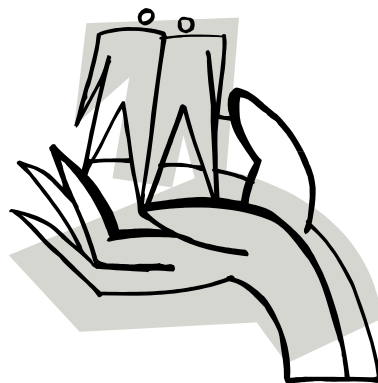
The fact that he doesn't quit doing things. He kept the same job he has had for three years, he pushes carts. I couldn't keep a job at Dunkin Donuts. I changed my job three times. I thought that was pretty good.

She's really smart at school.

I'm just proud of him, of all he can do despite his setbacks. I'm glad he's not a bitter person, that he's a good and positive person.

A lot of his accomplishments artistically.

I'm proud to know I have a unique, loving, caring brother.



Hopes for the Future

That she finishes college and gets a good job.

That she'll be happy with who she is. That she'll live on her own.

I hope that she'll be able to move out, live with an aide, and keep a steady job.

That he'll be happier.

I hope he can accomplish what is put in front of him and he doesn't get caught up with what he wants to do.

I hope he's able to get what he wants out of life, live on his own one day, have a steady job he likes, good friends and not have a lot to complain about! (Course he'll probably find something to complain about.)

That he can be more independent and we're seeing improvements in his verbal skills.

I hope he's able to overcome the things he doesn't like about himself.

That he enjoys life and doesn't regret being different.

That she'll have fun in her life.

That she'll keep on progressing.

That some day he will communicate better and tell us what he wants and needs.

I hope he gets better at being around other people.

He'll wind up being real happy, find a job he likes, and won't forget me!

That she'll be able to drive and make a lot of friends and become more sociable.

That he'll be in good health and that he'll be enjoying life.

That he can always be happy where he is and gets the treatment he deserves.

That he's able to take care of himself in the future.



Section III: Summary

The comments provided by adolescent siblings who participated in our study show a large range of experiences. Many talked about the happy times of having a brother or sister with autism, and how much they have learned about life. Their responses, at times, were very mature. Other comments show the difficulties and frustrations that siblings face. Clearly, there are both positives and negatives to growing up with a brother or sister with an autism spectrum disorder. This range of experiences is important because it gives us insights about the stresses of this challenge and also the factors that help siblings cope and be resilient.

We hope that in the future we can include these siblings again as they become young adults and make transitions to their own independent lives. We feel there is still a lot to be learned about these siblings' experiences and family relationships.

We hope you enjoyed reading these quotes. Thanks so much for your participation, and we look forward to continuing our work together!

A decorative blue banner with a light blue background and a darker blue border. The text "Thank You" is written in a large, elegant, blue cursive font. The banner is flanked by ornate, symmetrical scrollwork designs in blue.

Thank You