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Adolescents & Adults with Autism A Study of Family Caregiving



Report #3

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

- Principal Investigators -

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Acknowledgements

This project is supported by grants from the National Institute on Aging (R01 AG08768) and the Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago (H133B30069), funded by National Institute on Disability and Rehabilitation Research. We gratefully acknowledge the support from the Graduate School of the University of Wisconsin-Madison and the Nancy Lurie Marks Foundation that helped to launch this research. Administrative support for the study is provided by the Waisman Center at the University of Wisconsin-Madison and the Starr Center at the Heller School for Social Policy and Management, Brandeis University.

We are extremely grateful to the families of the 405 adolescents and adults who have given so generously of their time and shared their lives with us.

Cover Art: *Flowers* by Andrzej from Poland. From the Harvey A. Stevens International Collection of Art by People with Developmental Disabilities, sponsored by the Friends of the Waisman Center.

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or Sister with an Autism Spectrum Disorder**

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Section I: Introduction

Until now, there has been almost no research on the extent to which adult brothers and sisters of persons with autism spectrum disorders (ASD) feel their childhood was similar to or different from their others' experiences, the extent to which their adult lives have been affected by the challenges of having a brother or sister with ASD, and the extent to which they maintain active involvement with their sibling, or are emotionally and physically close or distant from their brother or sister with ASD.

We were eager to explore these important issues as part of our longitudinal study on families that include an adolescent or adult member with ASD. Over the last two and a half years we have conducted interviews with more than 400 families. Our research on the challenges and rewards families experience is the largest federally funded project ever conducted on this issue. Our study includes families at various life stages – with families whose member with ASD is as young as 10 years old and families whose member with ASD is now in his or her 40's or 50's. Some live with their parents, while others live away from home.

We are extremely pleased that over 200 adult brothers and sisters (age 18 and older) were willing to answer many questions and write about their experiences in their own words. We are delighted to share with you some of what we were told.

In this booklet, we have assembled some of the wisdom, reflections, and ongoing concerns that adult siblings expressed. Siblings also had advice for parents and other siblings. The quotations in this booklet reflect the range of thoughts and concerns that surfaced in this study. While there are many common themes among these comments, the uniqueness of each sibling's experience is also wonderfully evident. We have changed personal information to protect the identity of those participating in our study.

We are grateful for the generosity of so many busy people who gave so freely of their time to help us learn more about the concerns of adult siblings of persons with ASD. We look forward to continuing to learn together!

Section II: Reflections from Siblings

My Brother or Sister with ASD

...My brother is very warm and loving. His openness is refreshing.

...My sister can be exhausting at times.

...My sister is outstanding! She loves working and she does her best in spite of her disability. I admire her loving personality.

...At this point my sister is happy, but in the future I would hope to see her in a more independent living situation.

...He enjoys his videos or magazines or music tapes. He loves his sauna every night and yogurt afterwards.

...She currently doesn't have a job and sits and watches TV all day. Her weekends are busy with friends and activities, but she needs something to occupy her during the week.

...He is home with our parents and they all do very well and the house is full of love.

...He needs to be more active. He plays video games more than anything else.

...My sister loves my mother and it is good that they live together, but my sister is also very social and people her age should have more contact with their peers.

...He works on a daily basis. He votes and conducts his affairs just like any other citizen. He keeps his commitments and responsibilities.

...I feel that too much time spent on her computer isolates her socially.

...I think we have all realized that people with autism are really no different than people without. They just express themselves different.

...My brother has kind parents and a good home. He has a lot of problems that will be difficult when my parents grow old.

...I have an extraordinary family. My brother is an integral part of it.

...My brother has few friends, if any. He is very isolated and alone. This is frustrating and depressing for him.

...My sister lives alone and is doing quite well.

...Among people we know, we were unique in having an autistic sibling. We're proud of him, proud of my mother for all her support of him, proud that he's part of a close-knit family.

...My brother is a "couch potato" and loves to relax a lot. I wish he were more physically active as well as mentally stimulated.

...My brother shows us not to take life too serious and has taught us to be respectful of people with disabilities.

...My brother is kept busy but when left on his own, he will "tune the world out" by counting pennies or marbles and watching TV.

...My sister needs more structure. She becomes bored easily and secludes herself if she is not engaged in an activity.

...She just recently began attending college in my parents' hometown, with her own dorm room on campus, arranged through special health services.

...She does get to do some things she enjoys like swimming and visiting babies, but she should be learning new skills instead of working on an assembly line.

...He is very happy living at home. My parents are very loving and caring towards him. They have his best interest in mind.

...We all love my brother very much. My siblings and I have and continue to support my brother to the best of our abilities. He unites us.

My Childhood and Growing Up

...I definitely felt I had more responsibilities compared to friends. I grew up faster because of it.

...I felt very protective of my sister while we were growing up. I tried to help my parents keep the household running and spend time with my sister. I had more responsibility than most of my friends my age. But it was responsibility I chose to take on myself.

...While dealing with conflicts in the household often produced unfair results for me, I have come to appreciate the stressful situations my parents were forced to cope with, and how they did the best they could.

...My brother was a "bright" part of my childhood -- a good memory.

...I guess I've always felt like I've been 10 years older than my peers when it's come to responsibilities.

...There were more every day frustrations and more realization of life than you would expect at my then age.

...We were taught responsibility at an early age and I don't feel my brother added to that.

...I felt like my mom needed extra help so I stepped in and did what I could.

...My sister's autism pulled us apart and brought us together many times in the past and will probably continue to do so in the future.

...I am very proud of my family. My parents treated all their children with love and respect. They gave us many privileges as well as responsibilities.

...I have missed out on a lot of childhood experiences, but I developed a closer bond with my parents and my other sister.

...In adolescence, I felt it was a negative impact, but now in adulthood, a positive impact.

...I feel closer to my family because we were together a lot because they didn't go out much because they had to watch my brother.

...Autism affected vacations and outings the family could go on. That would be the negative side and the positive side would be that my family and I got the opportunity to experience and understand autism.

...I admire my parents for the way they raised us. My brother's disability didn't hold us back.

...My brother would occasionally destroy my books, toys, homework.

...It meant added responsibility and burdens at times. On the other hand, it has made my mother and me very close.

...It taught us tolerance and unconditional love and selflessness to see how our parents cared for our brother.

...You always had to know who was watching him, where he was, what he was getting into.

...I always felt like I had to be the strong or good child for my mother.

... It made me more appreciative/thankful of the family environment I had while growing up.

...I don't know if I had more, but the responsibilities I had were very different from the norm!

Community Acceptance

...I did not have many friends over to play as a child and if I did I had to explain our situation beforehand.

...We did not curb our socializing. Our friends and relatives seemed accepting of my sister even though they did not always understand her behavior.

... My parents couldn't participate in school or extracurricular activities because their duty was to take care of my brother; they still however contributed as much as they could.

...Well, I felt somewhat isolated. I'm not sure if we were.

...We have always taken my brother with us when we go places.

...Usually, when it came to most formal social occasions, only one parent could attend because the other would have to stay at home with my sister. i.e. school plays, ceremonies.

...My mother was very progressive thinking, inclusive and dedicated to trying to help my brother overcome his disability. Unfortunately the rest of society can't fulfill this standard for him.

...My parents never really went out for fear if he had an episode.

...We had great extended family support. I think this city is also generally open minded towards and accepting of autistic people.

...One parent always stayed home with him.

...Many people lack understanding or empathy when being in the presence of my sister to the extent where people may not want to associate. However, there are many people who are very understanding.

...At times we could not do things other families have done. We were forced to live by routines to accommodate my brother.

...My brother was and is involved in all family activities not treating him different. People in this area will walk up to my brother and greet him before the rest of us. That's good.

...I remember asking my parents why we couldn't do all the family activities that I saw my friends doing, Disneyland, going to restaurants more often, etc.

...My extended family has always accepted my brother with open arms and has always done their best to include him even when the situation was awkward or potentially embarrassing. For that I have the utmost respect and appreciation of my family.

...Some things we weren't able to do or only one parent was able to do it while the other had to watch him.

...My mother wouldn't allow us to be isolated. We had a fantastic neighborhood. My brother had friends and was included. He was a cute, loveable child so it was not difficult.

...My brother was included in all activities in and out of the house as long as he was comfortable

...It's hard to say - we never were a very community-oriented family to begin with.

...My brother was included in all our daily lives. He was treated like just another brother, but just a little special.

...My parents made it a point to participate in neighborhood/group gatherings as much as possible to try to socialize my brother and myself.

Relationships

...I have a great deal of respect for my parents. I became more open and honest with the both of them.

...The one thing I've learned is that no matter what happens, that if something were to happen to my sibling or vice versa we would be there for each other, no questions asked.

...My sister definitely affected who I chose to marry. My husband and my sister have a wonderful relationship and that is very important to me.

...It has formed a very strong family bond.

...I know I can't marry anyone who won't be supportive and accepting of the fact that one day I/we will be responsible for my sister.

...My family is closely bonded due in part to our similar experiences involving my sister.

...My sister likes my fiance and he is very nice to her. That makes me like him more.

...Of course he affected my feelings about my family because he was part of it. There are good memories and there are not so good ones too.

...I think she has made us a more caring family. My mother has always made us conscious of her and others.

...I think my father had a harder time accepting my brother's disability.

...It has caused me to gain so much more respect for my dad - seeing how he really rose to the challenge of my sister and has done so, so lovingly.

...My love and respect grew when I saw dad care for my brother. He always did what he thought was best for my brother.

...My mother and I are very close because of my sister. I think we both feel a need to protect her.

...It has probably brought us all closer together. I have and have had a greater respect and admiration for my mother.

...My husband is accepting of my sister, and I am proud of his acceptance of her. However, I sometimes feel that he doesn't understand how her condition has affected me and my family. This makes me feel as if he doesn't understand me fully.

...I think my family would have taught me the same values without my brother. I did learn a lot about life, living with him in our family. I learned that people can be different (very different) and still enjoy life and love.

...I think my mother appreciates my ability to understand and accept my sister, but also the strain and exhaustion of taking care of my sister stresses my mother and can cause more tension at times.

...My other sister and I have become much closer as we relied on each other for support while growing up with our autistic sister.

...I realized my mother is the strongest and most beautiful woman inside and out that I have ever known.

Children and Childbearing

...I feel that my relationship with my sister has strengthened my nurturing skills. However, I sometimes wonder if I could handle the challenge/pain/disappointment of a disabled child after knowing how hard it has been for our family.

...We are all children of God. Some of us - like those with autism - are very special. Among all the hardships, violence, and misunderstanding, I still must say, what an opportunity!

...I find myself having greater expectations for my kids. Maybe this is because I just want to make sure that they not have autism. I worry so much about it that I can't help it.

...Will I too have an autistic child? I worry sometimes if I have a child later in life could that child be autistic too.

...I went ballistic with fright if my children looked at their hands when they were babies. I rejoiced in their normal behavior and enjoyed the luxury of being able to attend to them and I was in awe of my mother.

...Nothing in life is guaranteed. Why should I worry more than anyone else?

...I waited a long time to have kids. I just wasn't ready. My sister really took it out of me. She is a good person but I couldn't handle all that stress. My daughter is fine but I still worry.

...My parents were worried about my having kids. I wasn't. Never even crossed my mind.

...I watch everything!

...You could not pay me to have any kids. Living with my brother has made me not want anything to do with kids.

...I will probably have children. If my brother lives with me while my children do, that's completely fine.

...I never experienced sibling rivalry. It is hard to deal with it with my kids. I had nothing or no experience to draw from. I did have lots of patience with my children.

...It has made me more inclined to have children but it has also scared me due to that fact that I could pass autism on to my children.

...I want to have a big family so if any of my children are disabled he or she will have more than one sibling to care for them.

...I don't know what I would do if I had a child like him. I'd feel bad, but I'd probably want to give them up.

...Made me appreciate the lack of health issues with my own children.

...I am terrified to have a child with a disability such as my brother's. I don't think I could handle it. Genetics counseling before planning pregnancy is definitely a necessity.

...I thought that I would worry but I don't. I love my kids and could accept anything that comes my way.

...I would still like to have children some day.

...I learned I can only guide my children. I cannot praise or blame myself for their actions.

How My Life Has Been Affected

...In my opinion, my siblings and myself included haven't moved very far away in case our parents ever needed anyone to be there or if something unforeseen happened.

...I don't take things for granted. I am grateful for health. I have much more respect for my mom than most of my friends have for their moms.

...Because I had a lot of responsibility as a child I have become a responsible, loyal, even-tempered adult. However, I also worry a lot!

...Having him in my life reminds me not to take my health, sanity, or freedom for granted.

...We never got to do normal things like go out to dinner or go to sporting events. We always had to worry about how my brother would act. No one would ever babysit him so my parents always had to stay home. I missed out on a normal relationship with my mom.

...You mature a lot faster in some ways and you don't take things for granted. In other words, immediate family comes first.

...I am a childcare provider and all of my kids are easy as pie. I'm great at my job. None of my kids compare to my sister.

...I think it's helped me to become more understanding. And to appreciate the options life has for me that won't be available to her because of her disability.

...I have always been depressed and lonely. I am not very confident.

...I am a teacher because I want to help children for whom learning does not come easy - like my brother.

...We are a very close family, and all are heavily involved with Special Olympics, which is a direct impact from my brother.

...I am willing to help people that are different from me. I am more understanding and now realize we all begin at different points. It is not even what we do but that we do the best with what God gave us. Everyone has special talents, even a person with autism.

...My mother has grown old and I regret not being close with her. She always had too much to do and not enough time for all of us. Sometimes I hate my brother for this but it isn't his fault.

...My sister has taught me to be more empathetic and listen attentively.

...I refuse to work in a field that even remotely relates to autism because I can no longer deal with it.

...I am proud that I played a positive role in her life when we were younger. I feel guilty I don't have the same relationship with her now. I feel as if I've abandoned her to pursue my own goals.

...Not much different than others. Some people have autism in their families and some people have other kinds of hardship. It is all the same.

...I learned everyone has a purpose in life and how to look for the best in all people.

...I look at other families who don't have children with disabilities and some have great relationships. Others on the other hand, don't have great relationships with their parents and siblings, so you don't do things as a family as much as other families do. You make sacrifices. You do without things. But in the end, you're stronger, closer, more vulnerable, more honest, a little more responsible.

The Future

...I worry sometimes how my life would be affected if something happened to my parents and I became my sister's primary support.

...I know I'll have to marry someone who will also care for my brother.

...I don't know the options. I would watch him but I can't do it alone. I would need help.

...I personally didn't plan for a future because I thought I was going to have to come back and take responsibility for my brother if there had been an unforeseen event. Now I know otherwise.

...I know I will one day take care of her, but she is very laid-back and not violent. I have no worries about it.

...My sister is happier living in a home. She has all her stuff and has a routine that she likes. She gets to go to a bagel shop every Sunday and gets to order her life how she wants. I would not make her happy. She needs the home to make her happy.

...My sister can't live with me. She doesn't listen and is rude. She would be a bad influence on my own kids. But I would visit her or help in some ways.

...I've already told my parents that when they die, I want my brother to live with me. We are good company for each other and I don't ever want him to live in a group home isolated from family.

...I worry a lot about what will happen when my parents die and somewhat resent that I will be the primary caregiver - which I'm ashamed about.

...I love him but I can't deal with all that he needs.

...When I get a place of my own, I think he should come live with me and my friends.

...I think having my brother living with me would be a strain on my relationship with my spouse.

...Our parents were always there for us. We would take care of our brother somehow. We owe it to our parents. They are good people.

...I would be very nervous. I don't think I could ever do as wonderful a job as my parents or understand him as well as they do.

...I worry a lot about this being a deterrent to people I date. It's often hard to be around my brother and I worry how I'll deal with it full-time.

...The responsibility of taking care of my sister would be a task greater than I could bear financially, emotionally, or successfully. Her needs require more responsibility than I could properly handle.

...It is hard to find a husband because my brother is a big part of my life and I will move him in with me when my mother asks me to. If I had a husband who wasn't supportive he would have to go because blood is blood.

...I would give my brother anything. I would love to have him with me, but he needs constant supervision and structure that can be better provided at a residential care setting. I also want to give my children (in the future) all I have and if he was with us, I know that would be difficult if not impossible.

...For my sister I think that best situation will be for her to live with me and my family. I have young children and want to give them the time they need from me. I hope that my parents' health will hold out several more years.

...It would be an extremely big responsibility and would change my life drastically.

...I know my parents worry about my sister's future when they are gone. They both have had recent health issues and it is made more difficult because they worry about her.

...I currently have no idea what my living situation will be like beyond college, but I get along pretty well with my brother, so I'm sure we could work out some co-living situation that wouldn't be a problem.

The Positive Side

...I learned to be responsible, and I know what it's like to have people rely on you.

...He has helped me appreciate the freedom I have—whenever I do something or go somewhere new and exciting, I get sad knowing he'll never be able to do such things, but at the same time I am reminded to appreciate it doubly for the both of us.

...Once my sister was diagnosed, I feel I've been very supportive. It's a wonderful feeling knowing I can help and that she feels she can reach out to me.

...Through her I have learned tolerance, patience and to be thankful for all that I have.

...My brother has such a different perspective on life and he makes life much more interesting. It gave me more of a focus for helping people in my career.

...Learned compassion, caring, understanding, more compassion to those in need. Kept my family close.

...Working together as a family to support my brother. Learning about Autism. Having a mother who was a strong advocate for my brother and a good role model for all her children.

...The adversity of parenting an autistic child made for a stronger family in my opinion, brought the remaining family closer and taught us firsthand the implications of a disabled child.

...I have learned to be less self-conscious and less concerned with what others think about me. I am more open to accept people who are outside of the "norm" in terms of behavior or appearance.

...Unconditional love. The "little things" that my brother does, his smiles, laughs; his sense of humor is wonderful. I am so proud of him—he's gone through so much and is a beautiful person who will be forever innocent. A child inside a grown body.

...Learning to avoid excessive self-centeredness, enhanced my interest in providing service to others who are in need.

...Made me defend the disabled more than I probably would have otherwise. Made me feel better about myself and any problems I might have.

...Seeing my brother grow over the last 10 years to have a real job and live at his group home, spending time with him and knowing he understands me and loves me, his laughter when I make a joke.

...Growing closer as a family through need and crisis.

...My brother has helped me to develop a real tolerance for other people- their abilities and disabilities, their differences. This will help me interact with others for all my life.

...I appreciate being a healthy active adult. I have learned to deal with the awkward feelings of having an autistic sibling with girlfriends, spouse and children.

...Learning about differences in others. Learning tolerance. Learning humility. Seeing my mother's strengths and having her as a role model. Learning to love my sister (and others) for who they are.

...I learned not to take life for granted and to respect a more diverse world. I feel I was opened to a lot more in general than kids in most situations as far as life is concerned.

...Increased appreciation for individualism/diversity, heightened personal sensitivity, appreciation for what I have, physically and mentally.

...I am very open to "different" people or situations. I have patience with young children or disabled people and I always choose to work with the "black sheep" of the group. I am also very sensitive to others feelings.

...I am stronger, deeper, better developed person. I learned the truest meaning of unconditional love and support because of my autistic brother. My perspective on life is bright and hopeful, and mostly optimistic.

...Overall, I think I have emerged as a more understanding person.

The Negative Side

...When my brother was little, he was very destructive and violent. I had a hard time as a child understanding why he would bite and hurt us and himself. It was painful to see him in pain. It is difficult knowing there's a smart boy in there but he cannot speak. Frustrating that my brother couldn't ever tell us what he was feeling. It also is "heart breaking" to leave him behind after a visit with him.

...My childhood was very stressful and embarrassing. I missed out on a lot of fun during my teenage years.

...My sister's autism is the biggest tragedy of my life—I love my sister and it has been painful for my whole family to see her robbed of her ability to communicate with us and participate fully in family relationships. I carry a deep sense of sadness and injustice with me always.

...Reactions of other people to my brother's inappropriate behavior. Feeling powerless to help him when autism "strikes." Seeing how frustrated he can get sometimes.

...Worries about his future. Anger at his failure or inability to understand the consequences of his actions.

...Living with my sister made my childhood unbearable. Between her physically violent outbursts, to her imposing rules and obsessions, life with her was a constant challenge. As a child (and teenager), I was very resistant to the controls she imposed on the household. I was often filled with resentment towards her, and my parents for trying to appease her demands.

...Too much static growing up; will never have a true sibling relationship; grew up "too quickly."

...Walking on eggshells, not having as many friends over when I was a kid.

...I learned at a very young age that life wasn't fair.

...Parents devastated by experience. Family very tense, unhappy place to be growing up. Lots of distractions—the day ran according to my brother’s schedule.

...Being in a public place, as a teenager, with my sister who was saying, doing and/or wearing something inappropriate would have had to have been the worst!

...Physical abuse from him when he lived at home. Being yelled at when he did something wrong. Not getting enough attention from parents.

...Being made fun of as a kid. Having to “take care” of my brother. Just having a different childhood than most (not so negative).

...Loss of “normal” time spent with my parents and siblings (especially at holidays). Tense, burned out parents. Feeling of not knowing how to help my brother.

...Frustration. He would get upset and could not tell us what was wrong. He could not speak. Another negative experience is when he would have seizures or temper tantrums.

...Hard to watch a person that’s out of control and can’t comprehend anything.

...Turbulent home life at times. Tantrums, relentless repetitive behavior, challenging patience.

...I have always felt guilty about having many talents when my autistic brother had none.

...Occasionally his behavior drives me batty.

...I always have to fight for him, since he can’t. I am single, but feel like I have been a parent all my life.

...I spent most of my childhood protecting her and explaining my “strange” sister. She is my only sibling and I miss having someone to share memories with. I do not look forward (although I will do so with love) to becoming her guardian in the future.

Advice from Adult Siblings to Parents of a Child with ASD

...Love your children all the same but differently. Be open, honest, and involve the sibling with things that are going on in the autistic child's life. Listen to advice and opinions of your children, because they might see it in another way that isn't all that bad. Try to do things as a family as much as you can, because you grow up too fast.

...Your disabled child is by necessity the center of the family and all activities are based around his/her special needs. Don't forget your other children. Do things with them with and without the sibling. Get a babysitter if you need to. All your children need some individual attention from you.

...Be patient and provide a structured environment.

...Make sure that you constantly communicate with your children about the autistic sibling's disability. Acknowledge that some of the sacrifices we are forced to make are indeed unfair, but sometimes necessary. Just keep an open line of communication.

...Try to treat all kids equally - share time and love with all kids. Create special time, projects, and show your caring for each child individually.

...Let them know that they have advantages that their sibling will never have and be grateful for them. Try to foster a close relationship between siblings by keeping them involved in his/her life and care.

...Let them know everything about the other sibling, and not hide anything. The other children need to know everything about their sibling and what is going on so that they can better deal with it.

...It is helpful to involve the other children from the beginning in the care of the autistic child. It is also important, however, to focus individual attention on the other children and to have frank discussions about what it's like to have an autistic sibling.

...Be open, honest, and available to talk about the child with autism. Respect all children's thoughts and feelings concerning a child with autism. Try to set aside some time for children without autism.

...Remember to spend some quality one-on-one with all kids. The autistic child requires more time and attention but don't forget the needs of siblings also. Involve siblings in the care and responsibility of the autistic child. Also, include them in meetings, discussions, etc. involving the child so they understand autism and understand their siblings.

...I know it's a big burden, but it's your burden. Don't guilt your other children into helping you with the autistic child. Otherwise there would be resentment. And don't forget that they have needs too, even if they seem insignificant.

...Make sure the "normal" child knows they are loved just as much. Take time to check up on them and communicate feelings about the autistic sibling and life in general. This should be two-way communication. It helps the child to know what the parent is feeling.

...Look ahead at the future of the child and discuss with rest of family—who will be legal guardian when parents die, etc. Work as a family to plan the child's future.

...Remember EVERY child has special needs that must be met. While one child may need more direction and instruction, make sure other children are getting additional emotional support.

...Keep all family members involved in sibling's situation, so they can be both a support network and help when things arise that are beyond your capabilities to handle alone.

...It is important to be sure the family's whole life does not revolve around autism. Don't let autism stop you from doing things out of fear. Your child with autism may surprise you (as will the reaction of some people). I never felt like my brother held me back and I thank my parents for that.

...You need to teach your other children to love and respect your autistic child. Continue to point out all the wonderful ways the child impacts the family and the positive lessons he/she teaches the family.

Advice from Adult Siblings to Teenage Siblings

...I'd encourage them to do whatever they can to promote good experiences with their sibling. It's not always easy, it takes work sometimes to "connect" with them.

...Don't feel a huge sense of responsibility. Live your life the way you feel you should. I'm glad to be independent, yet there is a part of me that feels I should be more in his life. And there's another part of me that knows I really don't want that.

...Keep it in perspective. No blame to anyone. Take care of yourself and your needs so as to stay strong and CLEARLY realistic for your sibling and those around you.

...Join a peer support group. Learn everything you can about the disorder.

...I would tell them to be patient and spend large amounts of time trying to connect with their sibling.

...Try and learn more about your sibling. Find out what he/she likes and how you can spend more time with them. Also, understand that autistic individuals have a hard time relating to other people. Lastly, laugh! Because if you focus only on the negative, you'll never respect/understand your sibling.

...Have open communication. If not with your family, then with professionals. Talking about fears, anxieties, etc., helps, rather than retreating into embarrassment or denial.

...Love your brother or sister—be there for your parents—understand why they do negative or positive behavior and realize they are not DOING IT TO you, only to express themselves with the way they can.

...Don't take things too serious. Try to be positive about things and involved in things as do other people. Try to treat your sibling as "normal" as possible. He/she needs attention just as does everyone else.

...It is difficult to grow up with a sibling who naturally required more attention—try not to limit yourself because of your family situation, i.e.- going away to college. Your family may be reliant on you somewhat to help care for sibling—but try not to forfeit life experiences.

...Don't regard your relationship with your autistic sibling as negative, or weird, or impossible. It can really be a unique learning experience. The more you get to know him/her, the more he/she will give you. The older you get, the easier it will get. I think that is, until your parents aren't able to provide/handle decisions regarding his/her care anymore. Try to bond with your brother/sister sooner than later. Don't pretend he/she doesn't exist because he/she will always be a part of your life in one way or another.

...Don't ever feel embarrassed! Your sibling is a human being with thoughts and emotions and is not trying to embarrass you. Have compassion and be proud of who you both are. It can be a confidence building experience. Other people are probably not judging you, even if they are ignorant of your sibling's situation.

...Develop your own peer group and pursue your own interests. Find a way to express your feelings, especially if your family cannot cope with your needs on top of your autistic sibling. Plan for an adult life where you can be an advocate and support person for your sibling without sacrificing your well-being.

...Hang in there. Things can get better. Remember that your autistic sibling has as much right to life, happiness and your parents' time as you do.

...Your brother or sister is more like you than different than you. He/she needs love, even though it's hard to try to stick by your brother or sister. If you were the one with autism, would you want to be alone? Find positives in your relationship and remember that you need to talk about it with someone- don't keep your feelings inside.

...Live your life to the fullest and appreciate the opportunities that you have that your sibling does not. Stand beside your sibling at all times. Support him/her and love your brother or sister. You will need to find a delicate balance in managing your life and your sibling's life. Lean on other family members and let them lean on you. Take time to be fully a part of your sibling's life. Know that you play a critical role in their future. Don't be held back, because of it. But know that family is always the priority.

...I would have to tell them don't be afraid of what you can teach them, or show them. Also, any of your prize possessions, keep out of their reach.

Section III: Summary

The comments provided by the siblings who participated in our study illustrate a tremendous range of experiences. Many described the joys of having a brother or sister with an autism spectrum disorder and how much they have learned. Others reflected on the difficulties and frustrations they have experienced over the years. Clearly, there are both positive and negative aspects to growing up with a brother or sister with this specific disorder. The importance of this unique situation is that it may offer specific insights about the stresses of this challenge and the resiliency of families who cope successfully.

Given the richness of feelings expressed in these comments from siblings, we are committed to including siblings in our ongoing research on family caregiving among families of adolescents and adults with an autism spectrum disorder. This component to our study is unique because there is virtually no research on siblings in relation to how they have been affected by this experience. We feel there is a vast amount of uncharted territory to discover with respect to our knowledge of sibling relationships.

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