Issues Facing Siblings of Children with Autism Spectrum Disorders

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Guest Speaker: Dr. Robert Naseef

Moderator: Okay. Hello everyone and welcome to Moms Fighting Autism. I’m your moderator, Nancy Bernatitus, and this is our 45-th webinar. Tonight’s webinar is entitled Issues Facing Siblings of Children with Autism Spectrum Disorders. We’re here with Dr. Robert Naseef.

Dr. Naseef is a psychologist in independent practice. Special Children, Challenged Parents: The Struggles and Rewards of Parenting a Child with a Disability, his first book, has received international recognition. He has lectured internationally and appeared on radio and television. He is the co-editor of Voices from the Spectrum: Parents, Grandparents, Siblings,

Dr. Naseef’s specialty is working with families of children with autism and other special needs. He has published many articles in scholarly journals and other publications. He has “a foot in each world” as the father of an adult child with autism. He has a special interest and expertise in the psychology of men and fatherhood. Through his experiences as a parent and as a professional, Robert relates to both audiences and is a sought after speaker around the country.

Rabbi Harold Kushner, the author of When Bad Things Happen to Good People, endorsed Special Children, Challenged Parents. In Rabbi Kushner’s words, “Writing with the wisdom of a mental health professional and the compassion of a loving father, Dr. Naseef has given us a book that will instruct and inspire us all.”

In 2008, Robert Naseef was honored by Variety, the Children’s Charity for his outstanding contributions over the past 20 years to the autism community. You can visit him on the web at alternativechoices.com.

Welcome Dr. Naseef.

Doctor: Thank you, Nancy. I’m happy to be here tonight. So I’m going to just talk briefly following the slides that you have on your screen and I’ll invite you to send in questions and comments and enjoy the presentation and see what it opens up for you about this important issue. Just in terms of putting it in perspective, I like this quote by Maya Angelou where she writes, “I don’t believe an accident of birth makes people sisters and brothers and makes them siblings, gives them mutuality of parentage. Sisterhood and brotherhood is a condition people have to work at” and I think all of us who have grown up with brothers and sisters know what she’s talking about.

This is life’s longest relationship and it can be very intensive times and it’s a very important relationship. Tonight we’re going to talk about what happens between brothers and sisters when a child has autism and we’re going to look from the perspective of what parents need to understand in order to be helpful to all their children, their typically developing children
as well as their child with autism. So, how to stay helpful and balanced in terms of the needs of everyone in the family. Too often and it’s understandable and almost inevitable, the family seems out of balance because of the tremendous demands that autism places on children and families.

So we’re going to think first of all and I’ll talk to you a little bit about our images of family life, where we get them and I’ll ask you to get in touch with your own images before you had children of what life would be like. We’ll discuss looking at ourselves as siblings because we are all siblings. Even as an only child, we have an identity as a brother or a sister or as an only child and then the impact of having a child on the spectrum.

I’ll ask you at one point to sort of switch places and imagine what it would be like if you were growing up with a brother or sister with autism, and finally we’ll talk about what we know that siblings want and need from parents and I think you’ll be able to figure a lot of that out as you follow along in this presentation. I encourage you to try to figure out for yourself what this means in your life as a mom, as a dad, as a brother, a sister, yourself and as parents to your children.

So let’s start by looking at ourselves and take a moment and just reflect on your own experience as a brother or sister or even as an only child. What was it like if you were the oldest? If you were the youngest? If you were in the middle? If you were an only child and there’s many variations. What if you were the oldest and a boy or the oldest and a girl? What if you were the oldest girl but the second born? What was that like?

So there’s just so many variations. There’s a lot of generalizations about birth order, but every family does have its own uniqueness. So it’s important to understand things that way. Just a birth order by itself doesn’t determine our personality, but it may have something to do with it. So this may not be always easy to think about, but I would encourage you to just spend a moment and look back at your own experience growing up. Does anybody want to comment on that?

**Moderator:** I’m a baby.

**Doctor:** Ah. What was it like to be the youngest?
**Moderator:** I’m the youngest with the most responsibility. Go figure.

**Doctor:** So were you the only girl? Is that why that happened?

**Moderator:** No. Two boys, two girls. I was the one that lived closest.

**Doctor:** So you kind of inherited your parents.

**Moderator:** Yes I did.

**Doctor:** So thanks for sharing that. So that’s not the most usual situation, but we all have our own particular experiences and we carry them with us and sometimes those experiences inform our lives as in our own families that we’ve procreated. So sort of keeping that in mind where you fit in the birth order, what your experience was and what your experience is now within the family you were born in and then within the family you have procreated.

We come into family life with images, dreams, fantasies, an idea of what things would be like. We have ideas from how we grew up, things we want to do the same, things we want to do different and most people want to have more than one child. In the modern world, some people now do choose to have one child, but generally speaking people choose to have a set of children, two or three and that will be a cozy little situation. So I’ve just included some pictures here of cozy little situations. Here’s a dad playing with his boys, a mum with their kids at the beach.

**Moderator:** Dr. Naseef, let me interrupt for just a second.

**Doctor:** Sure.

**Moderator:** My slides aren’t advancing so I’m assuming nobody’s is. Can you flick the triangle at the bottom of your slide box so...

**Doctor:** Oh, I was scrolling down the side. Oh, okay.

**Moderator:** No problem.

**Doctor:** All right, sorry everyone.

**Moderator:** That’s okay. Now we’ll catch up.
Doctor: Right. All right, these are the pictures of the cozy little sets of kids and not that yours aren’t cozy, but they might not be quite the same. Yeah, here is the mum with the kids at the beach. Now everybody is seeing what I’m seeing.

Moderator: Yes.

Doctor: So if you were the oldest, what was that like? Were you responsible for a lot? Did you have to take care of your brothers and sisters or look out for them? Was more expected of you? Were you like the little mum or the little dad? People born first are often high achievers, often leaders, because they kind of learned it growing up. That’s not always true, but it’s often true. Were you a middle child and what are some of the generalizations? Middle children often are mediators, conciliators. Sometimes they get lost in the shuffle between the oldest and the youngest. But they’re often very good at seeing different points of view because of their position in the middle.

They tend to be very understanding and while the oldest might be leaders, the youngest might be mediators and facilitators, negotiators. They seem very good at it. The oldest is used to taking care of people. The middle is used to helping people get along. The youngest usually is more used to being taken care of, having people dote on them, having the older brothers and sisters that adore them along with their parents and actually I’ve got a typo here, the bottom line should be an only child.

If you were an only child, you probably tended to mature quickly. You’re more used to hanging out with parents. This could be an asset as you developed. Being able to deal with authority figures better. But if you were an only child, you may have longed for brothers and sisters, dreamt of them, asked for them for presents and things like that and this would certainly be a part of what you’re carrying with you as a parent and wanting to have a set of kids and have them have each other. An experience you didn’t have. So often in a general way, we want to give our kids experiences we didn’t have that we would have longed for and how we grew up, our position in the family in its own way plays into this.

So as we become parents, where I’m leading you with this is we kind of have one foot back in the world of our own childhood and the family we grew up in. We’re carrying that experience and our other foot in the world
of the family we procreated. So two different experiences, similar and different. There’s probably folks here who grew up with a brother or sister with special needs and if that was part of your experience, you may have been more prepared than some of the rest of us for having a child on the spectrum.

Some people grew up with a brother or sister with autism, although it may not have been diagnosed as such in the past. So all these things we’re carrying with us and I’ll invite your questions as we go on later about these situations. Here’s a picture of my son Tariq. He’s now 33 and my daughter Antoinette, now 31 and you could see he’s – well we would say stemming on that leaf. It’s Fall and he’s interested in that leaf, but not interested in his sister and she spent a lot of her early ears wanting to play with him, wanting to engage him and he was far more interested in his routines and things than in people and that included his sister who was too young to understand that at the time, and so I ask you to think of if you were the little brother or little sister or the older brother or the older sister whose brother with autism wasn’t interested in playing with you, what would that experience be like? What would you feel? What would you think? What would the impact be?

Sometimes, and this can be a troubling part of the experience, the younger child may surpass the older child developmentally. So if the older child is on a spectrum and the younger child isn’t, the older child may always be the baby of the family and the younger child doesn’t have a role model and doesn’t have a normal playmate and may even call the older child the baby because the older child developmentally and in terms of life skills is the baby of the family and this can be a particularly hard experience for parents to be going through.

So just some thoughts about parenthood, and this is one of my favorite books about parenthood. It’s not an autism book. You may enjoy it because sometimes we get immersed in the world of autism and can lose perspective on the larger world. The birth of the mother is about how the experience of motherhood changes a woman forever. This book also includes a chapter about fathers and a chapter about children with developmental disabilities, placing this whole experience of motherhood and fatherhood, but mostly motherhood, in this broad perspective.
So and one of the points that the authors make, they’re both child psychiatrists, is that when you have a baby, there’s two other births. The woman at that moment in times becomes a mother and the man becomes a father and thus the family is born and this experience of parenthood really changes us at every moment going forward. So the authors of this book talked about the emotional trauma that’s chronic that parents may be experiencing and I think some, not necessarily all families that have children with autism, may be experiencing a chronic emotional trauma.

Let me put it this way. The birth of a severely developmentally delayed or handicapped baby is a trauma virtually stops time in its tracks. Suddenly your future is unpredictable and emotionally unimaginable. At the same moment, your past full of hopes and fantasies of pregnancy is obliterated and becomes too painful to remember. Parents are held prisoner in an enduring prison.

Autism does indeed seem to stop time in its tracks. The future is largely unpredictable and sometimes unimaginable. But today we’re going to be looking at how to wrap our minds around being a good parent to our typically developing children and how that is possible given the challenges of autism, and while it might often seem overwhelming in terms of responsibility, there’s ways to think about this that bring it into the realm of possibility and in fact make it look, while not easy, more simple in what we need to do to approach and succeed as parents.

So just briefly the stages that we might go through upon diagnosis are first some sense of denial or shock or disbelief. That’s normal and natural. It’s just human. It takes time to wrap our minds around autism and at times, new things happen, challenges occur and we might go through some of these stages again, starting with denial, moving to anger. Why me? This isn’t fair. Anger at the world, possibly our partners, possibly the medical or educational community. Some of that anger is normal. If this becomes chronic bitterness, that’s not helpful. If it spurs us into action on our children’s behalf, that’s usually helpful.

Bargaining or looking for a cure. I think most of us have spent some time there. Again, it’s normal and natural. Depression, sadness that persists. We may go through periods of depression. Again, a normal response, but not a comfortable one. But ultimately, while we don’t like autism, while we
certainly would want to change it, we move toward acceptance. We move toward finding out what we can do about it. Doing our best and letting go of what’s unchangeable while working hard to help our child develop, to keep our family together and to make a good life for everyone.

So acceptance doesn’t mean giving up. In my framework, it means doing our best and letting go of what we can’t change in the process. So our typically developing children also can lose their dreams and our children with autism can also experience some sadness about being different. Although often it’s important to distinguish whose grief it is. I’d call your attention to an essay by Jim Sinclair called Don’t Mourn for Us. He’s an adult with autism and he understands that parents may grieve and that it’s natural, but don’t assume that your child with autism isn’t happy or is grieving all the time. Just a wonderful essay, Don’t Mourn for Us.

So at this point, I think I’d like to switch to a short video that we have for tonight which was recorded at a conference featuring Floor Time in Washington DC. I think this conference was around the year 2000 or so and at the conference there was a panel of family members, parents and grandparents and a sibling. We’re going to hear from Catherine Flashen who’s a sibling of a brother with – the younger brother with autism and I think this is about nine minutes.

**Moderator:** For those of you participating via the internet, you can click on the link in your blue box where you clicked slides. It says video of Catherine. It will open in a new window and then when the video is done you can return back to this window with the slide show. Dr. Naseef, if you plan to watch it as well, you’re going to want to mute your laptop or your computer so we can’t hear feedback.

**Doctor:** Okay. So I need to listen on earphones. Will that work?

**Moderator:** Yeah, you can do that certainly.

**Doctor:** Okay. All right. So are you going to start it, Nancy?

**Moderator:** The participants can start their video whenever they’re ready.

**Doctor:** Oh, I see. Okay.

**Moderator:** And I will also follow along so I know when everybody is just about done.
Doctor: Okay. Good enough.

Moderator: But I can’t hear it. I have my computer muted. Dr. Naseef?

Doctor: Yes. Hi Nancy. So we’re back.

Moderator: Did you finish your video?

Doctor: Yes.

Moderator: I did too.

Doctor: So I think it might be good at sort of pause a little here and see if we have reactions.

Moderator: Let me blow my nose maybe.

Doctor: Yeah.

Moderator: I have a daughter who is an older sibling and takes care of her brother and that hit way too close to home. If anyone calling wants to ask a question of Dr. Naseef or make a comment on the video, press star 2 and that will alert me that you have a question. You can also submit your question through the web.

Doctor: I don’t think I showed this when I was in Dayton, but I show it often and there’s often not a dry eye, including mine.

Moderator: Yeah. It’s difficult to yell. I can’t go there. It’s too painful.

Doctor: You mean to where your daughter is?

Moderator: Yeah. To think about what it’s like for her.

Doctor: Well, there’s two sides to it. There’s what typically developing children is what we all can learn in terms of compassion and patience and simultaneously how the experience might try our patience.

Moderator: Christine from Downingtown says, now that I’ve heard Catherine’s articulate share, I understand more why my youngest has so much anger towards his older aspy brother. The question is what to do and how to find balance and I’m sure that’s where you’re going with this presentation.
**Doctor:** Oh, sure. The very first step and a powerful one – and was this an older or younger sibling that you’re saying?

**Moderator:** Why my youngest has so much anger towards his older aspy brother.

**Doctor:** Right. So the most important thing is just to let your youngest know that you understand that it makes sense. That will be a great relief to just validate that feeling and sometimes the way to do that is to say, sometimes it bothers me too or like he may not want to be that way. I think the show Parenthood on NBC now also depicts this kind of situation and often does a pretty good job of it with Max who is 12 and has asparagus.

So I’d encourage people – that’s fictional, but a pretty good representation. Anyone else?

**Moderator:** Yeah. We had a couple of comments. Nancy from Laredo says, can you comment on how a younger sibling can come to a realization that his older brother does have a disability and how he might feel a loss quite suddenly. My youngest son is going through this now. How can it be fair? So wanting to know how to help a younger one cope with the realization.

**Doctor:** Well, we want to and we’ll get more to this later, but I think it’s good to just respond as we go too. We want to give our younger children information about autism. Just like us, they want to understand it. Just like us, sometimes it’s baffling. It’s different and they need information at their level. There’s children’s books about autism. There’s all sorts of resources now on the internet at Autism Speaks, the Autism Society and various organizations. Materials for brothers and sisters. Also siblingsupport.org and I’ll talk about that a little later is a great website with resources for brothers and sisters. A list of books at different reading levels and age levels that are full of the challenges and the joys and benefits of growing up with someone who is different.

**Moderator:** And just two more comments. Jennifer from Pikeville said, this is hard to hear from a child’s perspective. My autistic son is the youngest of four and she’s kind of where I am. Mine is the youngest as well.

**Doctor:** Okay. Well, when we talked about birth order, I think that often if the youngest child has autism, it is a little easier because then the youngest is
always acting like the youngest. So in terms of birth order, there’s a little bit of a silver lining. You as a brother or a sister you expect to look out for your younger siblings. So there’s a natural part of this and that’s also like why I wanted people to really hear that raw emotion of a sister. At the same time, there is a natural urge that we have to help our brothers and sisters and both things are going on and it’s confusing at times and it’s important to validate both sides of this. Our typical children want to help, but it’s important to temper expectations for them and for the family in terms of what that help means and who’s responsible for what.

**Moderator:** Sheryl from Richmond said, after seeing this video the first time with Dr. Naseef in Richmond, we started talking openly with our typical son about autism and arming him with information. We also found him a child psychologist to talk to about how he feels about this without us parents being around.

**Doctor:** Wow, so it really helped and I’m glad to hear that and people always react to this video and I think just hearing it from a young person’s point of view really helps us understand our other children better than hearing it from anyone else or reading it. So I’m happy to hear that and that this has had an effect for Sheryl and I think you’re going to have a similar effect for people who are watching and listening.

**Moderator:** I know for my daughter she’s afraid to articulate how she feels because it seems selfish or self centered.

**Doctor:** Right. She wants to help and it’s hard to admit that it’s hard sometimes and I think that’s natural. It might help someone like your daughter if there’s a sib shop then in your area or somewhere where she meets other siblings and they talk with each other. That is often a lot easier than talking to mum or dad as talking to someone else in your position. I think often our typically developing kids see us struggle and they don’t want to burn us and sometimes in that sense they take on too much. But they’re trying to help us as well as their brothers or sister. In a lot of areas there are sib shops that different agencies run and they are a good thing to check out for your typically developing kids and they offer them at different age levels. Nancy, I’m getting a low battery on my phone beeping.

**Moderator:** That’s not good.
Doctor: But I have a direct landline. Should I hang up and call back in?

Moderator: Go ahead and call in via the landline while you stay on your...

Doctor: Well no, this is just a cordless. I’m not on the cellphone. Should I call in on the cell?

Moderator: No, I wouldn’t recommend the cell. Do you have a corded landline?

Doctor: Yeah.

Moderator: Okay. Yeah, go ahead and call in with your corded one then so we don’t lose you completely and...

Doctor: All right. Yeah, because that’s what going to happen in a minute. I’m going to get back to – what’s the number to call in again? I don’t have it handy.

Moderator: Are you ready?

Doctor: Yeah.

Moderator: 51 –h, this is mine. Sorry, my local number. You probably don’t want that. 949-333-4806.

Doctor: And do I need a presenter’s pin or something?

Moderator: Yes. And I don’t like to share this with everybody out there.

Doctor: Maybe I can find it. Hold on.

Moderator: Can I give it to you because it’s kind of – are you on your computer now? I can send it to your email.

Doctor: Yes, send it.

Moderator: Okay. There you go. Okay. So let’s see. I’ll just read some of the comments that have come in while you’re switching phones then.

Doctor: All right. I’m just waiting for that email.

Moderator: Okay. Yeah, it’s sent so hopefully. So we had Gerald from Fountain, Colorado say he has three autistic brothers so he’s the one that feels different. I can’t imagine.
Doctor: Wow. Okay. I’m going to hang up and call in.

Moderator: Okay. Talk to you in a minute. We had Tammy from Punxsutawney. She says she’s feeling that this could have been written by her own son. I too feel that way. It was really hard for me to watch the video because it could have been written by own daughter who’s 19 and she cares for her brother who’s 14 and it has really changed their relationship. I don’t know if you guys are experiencing that as well, that when you have the typical children babysitting or caring for their disabled siblings, it changes the relationship from, well what we’re experiencing is that it changes the relationship from being a brother and sister sort of typically combative relationship to one where one is in authority and one has to sort of comply.

Doctor: Hi Nancy. I’m back.

Moderator: Oh, you’re back? I almost talked you right back in. So I was just sharing that we’re experiencing a change in the relationship between our children where my daughter cares for my son so it’s more of a provider child relationship as opposed to siblings where they could probably pick on each other a little bit more, now families to be a little bit more compliant.

Doctor: So as he’s getting older their relationship is changing?

Moderator: Yep.

Doctor: And someone called in who has three siblings on the spectrum?

Moderator: Yeah. He posted the question or the statement through the website.

Doctor: I see.

Moderator: Yeah. Gerald from Colorado says he has three autistic brothers so he’s the one that feels different.

Doctor: Right. He’s left out. They have something in common that he does not have with them. So that’s really a twist on the situation. But he knows all too well in the family what it’s like to be different. In the world outside the family, his brothers are more different than he. So that’s just a unique and somewhat different slant, but not easy for him, not easy at all.

Moderator: No.
Doctor: And there are a lot of families these days with two and occasionally even three children with autism.

Moderator: Yep, unfortunately it’s very true.

Doctor: Any other comments or questions?

Moderator: Amanda from New York asks, how do we balance shielding and forming the typical developing children? How do we balance giving them responsibility and giving them time off so to speak?

Doctor: Okay. So let’s start to get into that. I want to go back to the slides and here’s a way that I use to discuss this with parents that I think tends to be helpful. As opposed to kind of sitting around and thinking, what should I do? What should I do? What I should do? If we imagine life as a boy or a girl growing up and having a brother or sister with a disability, autism in particular is what we’re talking about tonight, what would that be like? What problems would you see if it was you and I’m sure some people listening did grow up with a brother or sister with a disability and that experience may have prepared you somewhat.

But what would the problems be if you had a brother or sister with autism and what would you wish your parents would do? What would you want from them? What would you yearn for? So let’s just everyone think about that as we go and I’ll invite you to share your comments in this vein. If you were a brother or sister of someone with autism, what would you want? What would you wish from your parents? So call in or type in. Let’s hear from you.

Moderator: So if you’re listening via the phone you can raise your hand, let me know that you have a question, you want to talk to Dr. Naseef by pressing star 2 on your phone. Those of you who are participating via the web, you can put your questions or comments in through the website and they’re coming up fast and furious. I can hardly even get through.

Doctor: Great. This usually works. It even works on the web. I’m really happy to hear this. What are people saying? What’s the chatter?

Moderator: Well, Pisha from Los Angeles says, I exhaust myself so that our 10 and 9 year old daughters don’t suffer because of our 7 year old autistic son. I can definitely relate to that, having two older typical kids and then Sam
came along who require so much more attention and intervention that I had the other kids and everything. Soccer and sports and scouts and everything that we could think of just so they would have as close to a typical childhood as possible. I think that’s a great comment.

**Doctor:** So to state it in the sense of what you would want if it was you, as typical a childhood as possible.

**Moderator:** Yeah.

**Doctor:** Would be what you’re yearning for.

**Moderator:** Yeah. Well, that’s what I wanted for them. So that’s if I would have been...

**Doctor:** If it was you?

**Moderator:** That’s what I would have wanted.

**Doctor:** Yeah. It’s an easier way to think about it. There’s a little more clarity if we can switch places and see the world from that point of view just for a little bit.

**Moderator:** Their childhood was so much more different than mine because I was basically raised an only child, being the youngest of four who were much older and the world revolved around me. So basically I was Sam as a child. So I was the center of the universe and my kids were not, my typical kids. So it was completely different. If I were them, I guess I would want the world to revolve around me.

**Doctor:** sure. It’s just human. As a child that’s what we want.

**Moderator:** Yeah.

**Doctor:** We want to be noticed. We want to be special.

**Moderator:** As a parent I try to give them as much of a typical what I thought would be a typical childhood. But how much of it did I succeed at or how much of it? It really did revolve around what Sam was able to cope with. We can’t go there and we can’t go here because he can’t cope. Can’t do that. So Tammy from Punxsutawney says I would wish that my parents would
not ignore me and pay more attention to the siblings. Kim from Wyoming...

**Doctor:** Would not ignore me? Okay.

**Moderator:** Kim from Wyoming says more one on one time just for me. It’s a common thread here we’re seeing that people would not want to fall into the background. Amanda from New York says, I would want to know how to connect with them, how to get them to want to do things with me. Apparently the special rehab.

**Doctor:** Sure.

**Moderator:** I would want to be able to teach them things. I would want it to resemble a normal relationship.

**Doctor:** See that’s the yearning to connect that is also there along with some of these other feelings like don’t forget about me or I want some time with you too. But there’s also how do I build a relationship? How do I help my brother or sister? How do I teach them something? All this is important in understanding the entire experience.

**Moderator:** I think Rosemary from Seattle hit it right on the head here. She says, I would want my parents to support my sibling to share attention with me rather than I have to work so hard to get my sibling’s attention. I do not want to be a junior therapist. I want to be a sibling who’s noticed and an equal member of the sibling group.

**Doctor:** Wow. A sibling, not a therapist and you know what; it’s what parents say also. I want to be a mom, not a therapy dad or I want to be a dad, not a therapy dad. I know a doctor who has a boy with autism and he says, I want to be his dad, I don’t want to be his doctor and so there’s this yearning that we all have and that was Sarah?

**Moderator:** It was Rosemary from Seattle.

**Doctor:** It was Rosemary from Seattle. So Rosemary did hit it. I think she hit it right on the head there. She just wants to feel like part of the family and on an equal footing and just a brother or sister, not responsible for therapy. So when somebody’s too responsible this is the – or if life is just therapy, this is the reaction and in some of our homes for quite a while
and it’s inevitable, life does seem like therapy. Anyone else? Any other comment before we move on a little bit?

**Moderator:** Well, this is interesting. This is Joshua from Fountain, Colorado. Obviously the brother of Jordan that we heard from earlier. Gerald from Fountain Colorado and this is Joshua from Fountain, Colorado. He says that he has two autistic twin brothers who are more severely diagnosed and they need a bit more attention than I do because they can’t talk. How would I make my parents know that I feel slightly left out?

**Doctor:** And he has autism?

**Moderator:** Yeah.

**Doctor:** So here, what we’re seeing here is that even within the spectrum of autism, there’s differences and someone can feel left out because his younger siblings need more attention than he does. So thank you for sharing that. That’s very profound and very helpful for us all to think about. That also and here’s the bigger point, our child with autism is also a sibling and experiences life as a brother or a sister and may feel left out at times, rejected at times, wanting to participate in different ways than they’re able to. So the child with autism should also be understood as a sibling of others. So thanks for sharing that. That’s really important that we hear your perspective. Anything else, Nancy? Anyone else?

**Moderator:** How about this one from Audrey in Alabama. She says to see me for my special talents instead of how well I can cope and accommodate.

**Doctor:** See as we get these comments, I think we’re getting a fuller picture. So see me for the special person I am. See what I can do. Notice me and in that sense, we all want attention. We want to be noticed as the unique person we are. So I hope everyone is finding it helpful to think and look at life this way and I think it’s going to help you going forward because we can actually treat each child as special and unique.

We cannot equally divide our time even amongst typically developing siblings if there was no child with autism. Our time could not be equally divided. Children are at different levels and have different needs. What’s in the realm of the possible is treating each person as unique and special.
So that’s the framework that we want to be thinking in as we go forward tonight. Anyone else writing in?

**Moderator:** Oh, lots of people. Let’s see.

**Doctor:** This is great.

**Moderator:** Becky from Chester says that I have needs too. Anne from Texas says, my older typical child says that the younger child is the favorite. I hear that. With your attention, fair and equal treatment. Andrea from Philadelphia says, I would want fair or equal treatment even though we always tell our daughter that Sarah is not always the same.

**Doctor:** You’d still want it though, right? Yes.

**Moderator:** Okay. I think we can go forward.

**Doctor:** Okay. Well this is great to hear all these responses and just that ability to switch places allows us to have compassion and when we have compassion that begins to change the situation in and of itself, that deep understanding of another person, of another point of view, in this case of our other child’s point of view that may not have had our full attention. So just being able to think and look at life through this lens can begin to make a difference in your family. See what happens, but see what else opens up in you tonight as we continue this discussion.

Next, I have a series of quotes from siblings and these came from a book I co-edited, Voices from the Spectrum that Nancy mentioned. It’s a book of 60 essays and it includes essays by parents, siblings, grandparents, 10 essays by people with autism as well as essays by professionals. So Kimberley Bittner is a therapist in the Philadelphia area and she grew up with a younger sister with autism and this is what she said. Growing up with a sibling who has special needs is not an easy road. Being the oldest, I became like a second mommy to Christie. I gave up a lot to play such a large role in Christie’s upbringing. I was always the quiet one everywhere we went and she’s quite happy as a therapist today. But she wrote openly about her experiences and that’s her and her sister.

Here’s – oops, let me go back. I was advancing the wrong way. So that’s Kimberley Bittner with her sister Christie. Here’s Catherine Flashen who we saw on the video and this you’ll remember what she said about how
life is not fair. Mine definitely is always the same. DJ first, me second and I think this really strikes at the heart of it. As long as he’s happy, my mom is happy. As long as my mum is happy my dad is happy, but what about me? That wanting to be noticed that she expressed so clearly.

Lydia Liang wrote about it this way. “I try to find positive things about my brother and really there are some. It’s great when he can make me laugh. I tell myself these things and I try to be grateful and not resentful that I have this unique brother. He’s my brother and I love him.” So she explains again for us these mixed feelings of resentment and yet love and just the deep attachment that she has despite the difficulty and I think these sentiments that we’re reading here really pop up probably in every family in different ways.

My daughter Zoe who was 11 at the time, she’s 18 now and she didn’t like writing at the time, but when she saw her mum and I editing this book, she said “what about me? I want to write.” So this is how she put it. “My brother always hugs my dad. Whenever we go canoeing, dad hugger. When we go hiking, dad hugger. Every time he’s around and I try to go near my dad, dad hugger,” and likewise this often resonates with people when I read this quote because the child with autism does seem to hog our attention and a lot of times it’s necessary and unavoidable.

So people always laugh when I read this and brothers and sisters certainly relate to it. I appreciated my own daughter writing it. So earlier and I mean just a little while ago, I asked you your reactions to the video. What I’m going to show you on the next few slides is what comes out when siblings are interviewed in research and informally, the things that they say they want and I think just thinking back about our discussion tonight, a lot of these things people came up with when we switch places. So siblings say they want parents to notice their accomplishments.

What about me? What do I have to do to get your attention and particularly in families of kids with autism, the brothers and sisters are used to this behavioral approach which is necessary in which we are praising every little thing that our child with autism does and things that other children don’t get praised for. Like that’s great, you hang up your coat. That’s great, you ate with your fork. Just the little things that we’re reinforcing in order to help our children learn and grow. But our typically
developing children often we’re not noticing their accomplishments. We’re taking them for granted. So siblings say they want to be noticed. They want a fair amount of attention and...

**Moderator:** Does that mean equal?

**Doctor:** That’s the way it comes out, right? Fair. Whether it’s possible or not.

**Moderator:** Does that mean equal or fair?

**Doctor:** What?

**Moderator:** Does that mean equal or fair?

**Doctor:** Well, it depends who you’re talking to when you mean by it. So for some people it’s synonymous with equal. So I try to reframe it and say, what’s fair is to treat each person as special and give each person what they need and want. But it’s a hard balance. It’s a hard balance, but wanting to be noticed, wanting to matter and just like people said tonight, time alone, time one to one with parents. Time alone with friends because the brother or sister with autism can really be embarrassing.

Once a kid hits middle school and high school, they want to be able to see their friends around. They want freedom to complain and often that’s hard to do when your parents are overwhelmed. But they have complaints. They want to voice them. A family life as normal as possible and that came up tonight, and information about their brother or sister’s condition. They want to understand it, they want to help. So I think all these things were mentioned in our discussion. So really when we switch places inside us, we have a lot of the answers.

Here are some of the strategies in terms of how to do this. Listen actively to your children. Be patient. Hear what they really have to say. Active listening also means asking, paraphrasing what you heard, saying, did I get this right? Did that really bother you? Did that make you angry? Okay. What would make you feel better? Is there another way I can handle it and in this process you can serve as a model for your child. A model of communication, of opening your feelings. You can share some of yours, but again at your child’s level and not as a confidante. But if your child is angry, you can share, well sometimes I get angry. Sometimes I’m frustrated. Sometimes I don’t know what to do. By validating those
feelings, we help our children to know that they’re normal and natural. They may not be comfortable, but they’re normal and natural.

So that openness and honesty is important as we provide answers at our child’s level. So a young child who wonders like why is my brother or sister going to therapy? The answer may be fairly simplistic. His brain is different. He needs extra help because his brain is different or she needs that help because she doesn’t understand what you understand and as children get older, they need more information. They need to understand what autism is and they’ll have similar questions to the ones you and I have had and often still have.

We also want to notice the non-verbal cues. The things that kids don’t say. The expressions on their faces that when they leave the room because it’s uncomfortable or when they the many things that are expressed without words and we want to facilitate and be open to questions. Look for the questions. Invite them and sometimes you take a conversation as far as it can go, but you can always follow up later if you’ve taken note of what their concern is and you think of other ways to talk about it or you have suggestions. It’s important not to just sort of bury these concerns because they’re ongoing and our understanding is evolving and changing.

So another thing that came up was a sibling’s wish to build a relationship, to help out to teach their brother or sister. So here are some strategies in this regard. Have realistic expectations based on the developmental level of your child with autism. So you may have a five year old who is functioning like a two year old or an eight year old who is functioning like a five year old. But pick activities and toys that your children can interact with. It may be a little more simplistic than if they were typically developing, but helping to select things that your children can do together, things that the family can do together.

Model interaction, model giving positive feedback to all of your children. Limit and this came up, the care giving responsibilities, the therapy responsibilities. On the one hand, typical brothers and sisters want to help, but they don’t want to be burdened and while we’re doing all of this, be sure to recognize each child’s accomplishments. They are different. They’re at different levels, but everyone wants to be recognized and
noticed. So these are the kind of strategies that can really go a long way in maximizing the experience and minimizing the difficulties and maximizing the positive experiences that brothers and sisters have and mostly they all have them and they’re glad to share them also when we ask.

There also can be competition between brothers and sisters. So we have to be careful to give a good example in terms of resolving problems. We need to set limits on how far we’ll let an argument go. As our children are learning to cooperate, to give them recognition for that. Sometimes it’s really important to ignore some of the simple arguments and let them work it out themselves, thus staying neutral and consistent. There’s a book I’ll talk about later called Siblings Without Rivalry that talks about the strategies to deal with conflict amongst brothers and sisters and that book includes a chapter about children with special needs and the kind of conflicts that come up with them in their brothers and sisters.

So handling the competition and conflict is another important area to think about. Here are some of the books I recommend and any or all of these could be appropriate. Sib Shops is a book of workshops for siblings with children with special needs. It’s a good book for any school library. Many of you may live in areas where agencies like Ark or organizations like the Autism Society use the sib shop program. It was developed by Don Meyer. He’s in Seattle. I know we have listeners from Seattle and has worked out of the Kindering Center as well as Seattle Children’s Hospital.

Don Meyer is really one of the leading voices about the life of siblings. He’s a sibling himself and these workshops are appropriate for siblings for various disability situations. A book of essays edited by Don Meyer is called Thicker Than Water and this is a book by siblings like Catherine who we heard grown up. Adult siblings of people with disabilities. Many, many of these essays, I think there’s 60 or 70 were written by brothers or sisters of people with autism. They talk about what their parents did right in their mind, what their parents did wrong, what they learned from.

There are many, many positive accounts that also contain the mixed feelings, the difficulties as well as the benefits of what we learn growing up with someone who is different and growing up in a different kind of family. So Thicker Than Water is, if you want to continue to hear the
voices of brothers and sisters like the video tonight, I highly recommend this book. It is wonderful.

Special Siblings is a book about siblings from a parenting perspective, like how to help with the balance in the family. Mary McHugh is a professional writer, but on the cover she’s pictured here with her brother who grew up with a cognitive disability and she talks about her experience as siblings. She recounts her essays with siblings of children with autism and other disabilities. That’s the book on the left. On the right is my book, Special Children, Challenged Parents which Nancy mentioned and that’s a picture of me and my son, one day old and you can see he’s looking at me. The experience that many parents of kids on the spectrum had as our children were born seemingly normal for many or most of us and all these books are available on Amazon and book stores around the country.

Siblings Without Rivalry is the book I mentioned a little earlier. How to help your children live together so you can live too and it’s got a lot of comic strips with problem solving situations and a wonderful chapter about siblings who have special needs. Being The Other One is a memoir written by a woman who grew up with a sibling with special needs and a very powerful book. Boy Alone is a memoir by the brother of Noah Greenfeld. Noah was probably, not probably, he was the most famous autistic child of the ’70s or ’80s. His father wrote a trilogy of books about the struggle to raise Noah and eventually he needed a residential placement.

They’re not easy books to read. Karl Taro Greenfeld is Noah’s brother and he wrote from his perspective. It’s a very, very powerful book. Not an easy one to read, but an important contribution. Siblings of Children With Autism, a Guide For Families is a short and powerful book written by a psychologist who grew up with a brother with autism and her colleague. Another like very good book with strategies and insights into the sibling perspective.

Here are a few websites that I think you’ll find useful. Siblingsupport.org is the website that includes sib shops, the information on sib shops, training for people who want to run sib shops. A list of books, discussion boards, sibling conferences, etc. So it’s probably the best single website about issues facing siblings and a website where you can keep in touch
with everything that’s going on about sibling support around the country and somewhat internationally.

Siblingleadership.org is a group of adult siblings of children with various disabilities and if you go to this website you can print out their white paper which is their recommendations and policy in terms of policy as well as family life. Kidsource.com also has good sibling resources and at my website, alternativechoices.com are several articles about siblings as well as an opportunity to email questions and keep up with what we’re doing in our psychology practice. So, some internet resources.

Also I’d like to mention that I have an email newsletter. If you email me and my email address was at the beginning of the slideshow, I’ll put you on the newsletter list. I write columns monthly about family life with autism and other conditions. So when we look at in terms of overview, our sibling experience and if we think of ourselves as siblings as we did tonight, we can see it’s a complex and emotionally mixed and rich situation and of all relationships, it has some of the most mixed feelings in terms of love and hate, rivalry and cooperation, fighting and hugging, fighting and making up, jealousy, anger. We have a whole spectrum of feelings that plays out in a family and particularly between brothers and sisters, this can be very intense.

In modern psychology, probably the role of parents is emphasized while the role of our sibling relationships remains largely unexplored. It’s really common to talk about and think about how our mother influenced us and how our father influenced us. But the relationship with our brothers and sisters for all of us, not just our children, is very profound, very intense and can bear looking at and understanding. So I just want to sum up what we’ve been talking about and then be open for questions and discussion for the last half hour or so.

So if we want to restore some sense of balance in the family, start with ourselves. Start with understanding the experiences we bring to family life and being kind to ourselves about the situation we’re in and how hard we’re trying to be good moms and good dads. It’s important in that context to accept all of our children unconditionally. I know a dad of now a young woman with autism, but I’ve known him since his daughter was young and what he would say would really strike a chord. He said, “I wish
I loved my other children just as much and just the same way” and he was talking about an unconditional kind of love that I think children with autism can teach us and can teach us also that it’s important for everyone.

We have to let go of our images of the perfect or of sainthood as moms or dads or expecting our typical children to be perfect because we’re overwhelmed. I think we have to let go of that and know ourselves and know our children as the real people we are. Trying real hard, having some flaws, working hard to do our best with compassion for ourselves and our families. These are the covers of my books, Special Children, Challenged Parents, Voices from the Spectrum, the Book of Essays. Living Along The Spectrum is a DVD I recorded with Steven Shore who’s an adult with autism and a professor of special Ed and on the right, my voice, the book I co-edited with Dr. Cindy Ariel, my wife. Voices From The Spectrum which last year came out in Arabic. One of the contributors to the book is from Kuwait and she had the book translated and it’s being read in the Middle East as we speak.

So finally just in terms of the slides, the serenity prayer is quite apropos our overall situation and I call your attention to this particular translation. The serenity prayer was originally in German and the translations vary, but notice this, God give us the grace to accept with serenity the things that cannot be changed, the courage to change the things that should be changed and the wisdom to discern the one from the other. So while we are looking to let go of what we can’t change, we have a responsibility to change what we can change and in terms of our parenting of our children, whether typically developing or on the autism spectrum, we do have a responsibility to be as fair as possible, to treat each one as special and to work on the lessons that we’re all working on and that we’ve talked about tonight.

So from time to time, if you want to be touch with me you can visit our website. You can subscribe to my newsletter. Just send me an email and I’ll put you on it and I’m thankful to be able to participate in this with you.

**Moderator:** And the website is alternativechoices.com for those listening. I want to let the callers know that are listening via phone that if you’d like to ask a question now, just press star 2 and if you’re listening in through the web,
you can submit your questions directly to the website and they pop right up here on my screen. We have several people asking the twin question and that is like Alicia from Monesa Park. She says, what advice can you give me a single mother with a daughter who is a twin living on the spectrum? How do they find balance and how does she parent the non disabled twin?

**Doctor:** Well, I think the things we’re talking about tonight apply, but your situation is in many ways even more challenging. It can be really hard to be seeing two children the same age twins and one so different from the other and with twins in general, it’s important to treat them as individuals. People often have trouble with this and the twins themselves have trouble with this. It’s of all relationships, one of the most intense in the sense of the connection. There is and I would call your attention to this, there is a couple of Facebook groups for single moms and there’s wonderful discussions that occur on these Facebook groups.

It’s probably hard to find single moms as a group, but the internet does offer us this chance to do so and some of the people I know really get a lot out of the single mom groups because they can connect with people that would be hard to meet in everyday life. That being said, everything we talked about tonight does apply. The connection is really intense between your children and they are probably really longing to connect with each other. I have a friend with a situation like yours and they say that it’s like that relationship is where their child on the autism spectrum is learning the most because they have a brother or sister who is always trying to connect. So if you can facilitate that in any way, if you can help your typically or more typically developing is maybe the way all of us are, if you can help that interaction to occur, help them find things they can do together, you’ll really be helping and enriching both of their lives.

**Moderator:** I too have a friend that has twins. One is typical and one is autistic and she says that the typical twin often says that he can feel his brothers’ pain and that he’s probably carrying a lot of guilt she thinks from the things he’s able to do that his brother cannot do.

**Doctor:** Yeah. There might be some element and likely there is of survivor’s guilt. Like my brother has got it harder than me and some feeling of guilt about that.
**Moderator:** We had a couple of requests for you to put the serenity prayer slide back up.

**Doctor:** Oh, sure. Let me get it right back there. There it is. So I’ll just leave that there as we’re talking.

**Moderator:** There you go. So anyone calling on the phone, if you would like to ask a question, press star 2. This is the same sort of question here with the twins. Nadia from Montreal asks, my four year old nephew has autism and my sister is expecting another boy in April. Any tips on preparing a child with autism for a sibling?

**Doctor:** On preparing a child with autism for a sibling?

**Moderator:** Yeah. It’s kind of a twist on things here.

**Doctor:** Yeah, it sure is. The child with autism is not used to sharing his mum. So I think anything that helps with sharing is going to be good. But I’m not sure there’s a good way to prepare. Children with autism do tend to hog their attention, not because they’re selfish, but because they need it. But having that new baby coming is going to be a learning experience for everybody and certainly you’re going to change your sister’s family. But it’s great that you’re here and that your sister has you and that maybe you could think about this together a little bit and that your support in this situation. That’s just wonderful and a lot of people in the autism community would wish for a sister like you. So involved and concerned and really thinking about things.

So it’s just great to have you express that and I certainly wish you and your sister well. We learn a lot about kids and about parenting and about ourselves through having a child with autism in the family. So some of the lessons your sister has already learned and that you’ve learned will help with the new baby and it’s going to be quite a transition, but it is relatively slow. I don’t know the level of the child you’re talking about, but I’d say the preparation can come through particularly the visual, through books. There are books about having a new brother or sister. I would use those for a kid with autism, just like for any kid and I would be careful to give that older child who in this case has autism some way of helping with the baby, because the older ones usually want to help and the child with autism will probably be really fascinated. It’s easier to relate to either
younger people or adults. So the child with autism is probably going to be very interested and fascinated. Give him some things to do. So that’s just some thoughts on it and I hope it’s helpful.

**Moderator:** To go back to the hogging thing. That really hit home for me. Personally it doesn’t stop when your typical kids reach adulthood.

**Doctor:** Oh, no. I think you’re right.

**Moderator:** We just went through a situation with my daughter where she was very upset. Finally pulled out of her what was wrong and she was saying, Sam hogs dad’s time and I never get to spend time with my dad. So we’ve had to make some adjustments and of course if he’d only known that, he would have made time for her. But he just didn’t think of it. So in our family, it continues on even into adulthood where...

**Doctor:** Well, we’re our parents children all our lives. I think that’s absolutely true and profound, Nancy. Even after our parents are gone, they’re with us all the time. My father died in 2000. It’s not too many days that go by I don’t think of him. So as long as we’re alive we can work on the relationship and since the relationship isn’t over, your daughter can ask for what she wants. Your husband, her dad can hear her and life can go on with that understanding. That relationship, even in adulthood, continues to evolve. It doesn’t have to stay the same.

**Moderator:** Yeah, by definitely...

**Doctor:** It doesn’t change the past but it changes the present.

**Moderator:** I guess when we thought we had them all grown up it would all be fine.

**Doctor:** Oh, that’s all we want to believe. But really our job is not over and if we think about ourselves as our parents children, we know that it’s not. That we still wish and hope for our parents to love us in the way we want to be loved. We’re all like that. But it’s a hard job so we do want to just raise our kids and launch them and hope for the best. So that’s normal too.

**Moderator:** I as the mother have always been very aware of having individual time with each of the kids and being very meaningful in that and purposeful. But I never gave it a second thought that dad wasn’t doing the same
thing. So it didn’t dawn on me that they needed time with him too. I thought I was their entire universe.

**Doctor:** And you probably wanted to be enough too. That’s quite normal as well.

**Moderator:** What do you mean you need time with your father? What’s wrong with me?

**Doctor:** Why aren’t I enough?

**Moderator:** Okay. Marie writes, I’m trying to recover my son and have not told him what autism is. He is seven years old. I have not told his eight year old brother as they are best friends. How do you try to make sure the older one doesn’t get frustrated?

**Doctor:** Well, actually if you – there’s a really good YouTube video by Steven Shore who has autism who we mentioned earlier and he talks about how to explain this to children and I’d certainly suggest you watch his video. It’s about nine minutes. So if you go to YouTube and put in Steven Shore, autism you’ll find his stuff. But I do want to speak about this for a moment. I think your children are young and the important thing is not so much the label as helping them understand each other and giving your son a way to understand his brother and his brother is different. Just calling it autism doesn’t do that.

It’s explaining who his brother is that maybe his speech is limited. They need special help with that or maybe he has certain sensory differences. So certain things bother him. But it’s in explaining the difference that is the key and eventually, your son may need to know the label depending on how much progress makes. Now, while we all wish for recovery, even some of the more dramatic situations that we talk about, some of the symptoms of autism remain. So no matter how far you get with this, it’s unlikely there’ll be no differences from the norm. So just talking about those differences is where you start and where you go to is what you’re comfortable with and each person has to figure this out for themselves, but just start with helping to explain those differences.

**Moderator:** I had a very powerful anonymous comment come in or a question. Sometimes I feel that I should concentrate on the healthy child rather than lose both of them in the process.
**Doctor:** Wow. Well, certainly that does strike a chord because of the feelings of loss that we have often with autism because it feels often like a lost relationship and certainly if you’re coming away from this presentation realizing you don’t want to miss out on the other relationship, then you’re getting what I would hope you would get. Not to abandon your child with autism, but to bring a certain amount of focus to your other child who needs you, wants you, loves you and what I didn’t talk about tonight is what happens if a typically developing child doesn’t get some understanding from their parent, some attention.

That typically developing child may develop a symptom in order to get your attention if that’s the only way to get it. So it’s not – while it’s true that many siblings report the positive benefits of growing up with a brother or a sister with autism, some others develop symptoms of anxiety or depression or acting out that seem to work in terms of getting attention. So very important to think of each child and what they need from you. So while that’s a powerful and somewhat disturbing thought, I think it’s an important one.

**Moderator:** Yeah. It’s amazing how much power one little sense can hold.

**Doctor:** Wow, it really is.

**Moderator:** Along the same lines, Melissa from Maine asks, my son who is almost eight years old is increasingly concerned about our deaths and his future role in the caretaking of his brother who is three years older and has autism. Although I’ve expressed to him that his brother would be taken care of and his level of involvement with his brother will be purely his choice, his concerns persist. What advice do you have to help us alleviate his anxiety?

**Doctor:** Well, that’s a great question and I read a recent study on this. As I think what helps to alleviate his anxiety. His concern is normal. It’s a little excessive for his age, but that probably means he’s just a really sensitive, caring kid is as you have more specific plans as to how his sibling with autism would be cared for, you let him know the plans. What really helps the typically developing kids is knowing that the parents have a plan and what it is. Of course you may not have that right now. You probably don’t because it’s too soon, but you could talk about it in general terms. Like
that you’ll have a trust that you’ll make sure his brother or sister is taken
care of and that sort of thing.

My new book that’s in press now discusses all of these issues. It’s going to
be called something like Autism in the Family, Taking Care of Everyone’s
Needs. But this issue is what alleviates the anxiety of a typically
developing child about their parents death is to know there’s a plan. So
you’re on the right track. I just encourage you as you can to give some
specifics and to see how that goes and at some point your child may need
some professional help with anxiety if it doesn’t go away. So there’s
always that possibility as well.

Moderator: My daughter was about that age. She was about eight when I heard her
on the phone with her friend and she said, I can never get married
because I’ll always have Sam.

Doctor: Right. That’s a normal assumption.

Moderator: Yeah. It shocked me at the time because we had never, ever led her to
believe that he was her responsibility in any way.

Doctor: But it’s natural to think that. That’s shocking. It’s like it’s not what you
were thinking.

Moderator: No, not at all. No. We sat down and we said, that’s wonderful that you
want to be there for your brother, but what if he doesn’t choose you and
you’ve thrown your whole life around this plan and maybe he doesn’t
want to live with you. Maybe he does something else. Maybe we have
different plans for him and if he sets into your life at some point, that’s
great. But don’t build your life around him.

Doctor: Right. Absolutely.

Moderator: Christie asks, what is the best way to balance the parent’s expectations of
siblings to help the special needs sibling after we’re gone without creating
resentments? So there’s some expectation.

Doctor: Yeah, sure. Well, just an open dialogue, like how would you like to be
involved in your brother or sister’s life? What would you be comfortable
with? Kind of letting it be a choice and just keeping that dialogue open.
It’s a great question. In the families I’ve seen where this is a problem, it’s
not talked about and it’s like mostly the older generation of people who
didn’t have the kind of services and the kind of community that we have
today in the world of autism and they didn’t talk about it with their kids
and they got old and it was just assumed that their typically developing
kids would take care of things and where is the problem is where there is
no plan and then your child in a sense hurts this issue.

Without a plan, without discussion, without like working out what they
want to be responsible for and what they can be responsible for. So just
the fact that you’re talking about this and thinking about this, to me
means you’re on the road to working it out. Just don’t put in the closet.
That’s where the problems arise. When we look the other way and don’t
face the problem. The fact that you’re facing this to me means you’re
going to find the thing that works or the best way. So I’d just encourage
you to keep on the way you are.

**Moderator:** I think we kind of touched on this subject earlier. But Jewel is very
insistent that I ask her question. So Jewel from Louisville asks, I have 13
year old triplets. One is autistic. It is so difficult to watch two outgrow the
third. We try to be open about our frustrations as well as our love and
joys. I just don’t know how to make the autistic child understand how
come the other two are allowed to go out and do things. Any ideas?

**Doctor:** Oh gee. It’s hard to answer without knowing your kids. I’m thinking about
it though. I’m thinking about it right now. You might want to get some
professional input on this from someone who meets your kids and
understands their levels. But I think what you’re describing is painful and
is unavoidable for your child and for you. It’s quite normal and I’m
assuming from the question that your child with autism is relatively and I’ll
use it in quotes, ‘high functioning.’

Those children with autism who really understand their difference long to
be normal. They long to do what everybody else is doing and yet they
can’t always do it and our job as parents is to help them have as normal a
life as possible while simultaneously keeping them safe and not exposing
them to situations they can’t handle and having triplets really exacerbates
your job and certainly my heart goes out to you in this and I think it has
to be balanced in a special way and maybe it involves some safe trial and
error in terms of seeing what your child with autism can handle.
Sometimes a child wants to handle more and they – but we have to find out where the line is and that can be difficult. But just like with a typically developing child, it’s important that we validate the feeling that it’s okay to express it and that we’re always willing to talk about it and that you just over time work out what your child with autism is able to do, and sometimes the child surpasses our expectations. But we do have to be careful in this and I hope this is somewhat helpful and I wish I had a more specific answer. But someone knowing your children’s levels might have some more specific ideas on how you can deal with this.

**Moderator:** And this is also along the same lines. Lacy from Roxborough says, I have a 10 year old son and a seven year old. Well, 10 year and a seven year old. She didn’t say son. I interjected that myself. She has a 10 year old and a seven year old. The seven year old has ASD and her biggest problem is that the oldest one feels like his brother gets away with more, but it’s not the case. They do different things so they get in trouble for different things. How do I explain this to my oldest? I don’t want him to feel that I favor my other son. He does things to get attention, even if it’s negative.

**Doctor:** Well, it’s a challenging situation. I think what the 10 year old is noticing is that the rules are probably different. Like when he says my brother gets away with more, that probably has to do with his brother’s limitations and in some way validating that is important. Yes, they’re each different, yes there’s different expectations. But it’s important to see the world through his eyes. That there must be something to this, that he’s expected to do more and not that he shouldn’t be, but that the expectations are different. That he has a different set of abilities and what he regards as getting away with and this is a really common complaint of the typical siblings. Until they get to a point where they really understand autism, it can look like my brother or sister is always getting away with something.

But what that’s really about is the difference in their skills. So I would encourage you two things, to understand it from your son’s point of view that it looks out of whack and work toward helping him understand what autism means for his brother. It has a particular meaning and there’s something he’s noticing that’s important for you to understand in the process and it’s hard to hear that complaint. It’s really hard to hear that and I want you to know that part from me. It doesn’t mean that you’re
doing something wrong. It just means that this doesn’t – something looks like it doesn’t work for your other son. I hope that’s helpful.

**Moderator:** Even you’ll get that from just the typical kids. It’s not fair.

**Doctor:** Oh, yeah. It’s the most common complaint there is. It’s not fair. We’re all like that. It’s not fair, it’s not fair.

**Moderator:** Hope it’s not. Certainly not. This next question again hits especially close to home because we have a special needs trust set up for my youngest son and my older two kids are the co-trustees. So here is the question. Shannon in Virginia asks, we have a plan in place, but I’m out of the norm. Also hoping that my typical children will want to help watch out for their autistic brother. He’s 10 and high functioning and they are seven and a half year old twins.

**Doctor:** I think they will want to help with the trust. But they’re too young right now. It’s normal and natural to want to help out. So if and usually the ones you don’t want to help out are relatively rare and if that tends to occur when the family is really out of balance and they’re really not noticed and they just, the resentment grows and grows. So I would expect them to want to have a role and as they get older, you can talk about that. But I think they’re too young at this point. But these questions will inevitably come up and I’m glad you have a plan and that’s going to alleviate their worries about this. That’s great.

**Moderator:** So my oldest son is 21. You think it’s time I ask him if he wants to be a co-trustee? I figured I’d just be dead and gone and I wouldn't have to worry about it. Picky.

**Doctor:** Well, does he know there’s trustees?

**Moderator:** No.

**Doctor:** Well, again there’s no rush here. You have a plan and at some point, he’s either going to ask or he’d want to know or there just may come the right time to talk about it. But as long as there’s a plan and he’s not thrust into a situation he doesn’t want to be in, then he may not want to be a trustee.

**Moderator:** Yeah, I picture rain man where he has, is thrust into the situation.
Doctor: Oh, right. Oh, and you live near rain man.

Moderator: Yeah. Well, the time always flies when we do these things and it’s come to that point where we have to wrap it up.

Doctor: Oh wow, two hours.

Moderator: A request has come in for us to end on a positive note because we have talked a lot about the negative impacts on siblings. Is there something positive that we can leave with that they could get from?

Doctor: Oh, sure and I think that’s important. I’m glad someone brought that up. I certainly, while we’re talking about the problems, I think that in a very deep and profound way having a child with autism can really enrich a family and siblings learn tremendous lessons about love and compassion and growing up with their brother or sister who’s different teaches patience. It teaches love and creates really good people. Many siblings of children with autism want to contribute to their families and the world. They often choose jobs in the helping professions, not exclusively by any means, but it’s an experience that shapes us all and that can be a benefit to us all.

It’s important that we don’t look away from the problems, that we face them, that we look at them in the eye and find the best possible ways of dealing with them as moms and dads and brothers and sisters. So it’s that ability to face these problems that helps us make the best of the situation and there are tremendous benefits that many siblings as well as moms and dads report. So I wish you well on your journey and whatever was helpful to you tonight, hold on to it. If anything I said wasn’t helpful, you can just let it go and be well.

Moderator: And just one more time, your website is?

Doctor: Alternativechoices.com and I’ll go back to and my email is on the first slide. You can email me. Rnaseef@alternativechoices.com if you want to get my newsletter which comes out roughly monthly.

Moderator: Wonderful. I want to thank you for being with us tonight, Dr. Naseef. It’s always a pleasure talking with you and the siblings topic, very important, very important.
Doctor: Well, thank you Nancy. It was a pleasure to be here and it’s very meaningful for me as the father of a young man with autism to pass on the things that I’ve learned to others and I really appreciate the opportunity to be part of this tonight.

Moderator: We’re going to have you back real soon, okay?

Doctor: Okay. Thanks Nancy. We’ll be in touch. Great knowing you.

Moderator: Thank you very much.