Diagnosed with "Atypical Development and strong autistic tendencies" and "too sick" for outpatient treatment Dr. Shore was recommended for institutionalization. Nonverbal until four, and with much support from his parents, teachers, wife, and others, Stephen is now a professor at Adelphi University where his research focuses on matching best practice to the needs of people with autism.

In addition to working with children and talking about life on the autism spectrum, Stephen presents and consults internationally on adult issues pertinent to education, relationships, employment, advocacy, and disclosure as discussed in his books Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome, Ask and Tell: Self-advocacy and Disclosure for People on the Autism Spectrum, the critically acclaimed Understanding Autism for Dummies, and the newly released DVD Living along the Autism Spectrum: What it means to have Autism or Asperger Syndrome.

President emeritus of the Asperger's Association of New England and former board member of the Autism Society, Dr. Shore serves in the Interagency Autism Coordinating Committee, Asperger Syndrome and High Functioning Autism Association, and other autism related organizations.

Minta: Without further ado, Stephen Shore.

Stephen: It's a pleasure to be presenting for all of you on the topic of relationships and sexuality for people in the autism spectrum and how we can reach a greater understanding of how to support those with autism in this very important aspect of life. Let us begin. We'll start with a little bit about me. We're going to take it from the very beginning.

Things were pretty typical for me. My mother just had a two-hour labor. At 24 hours of age, my wife says I looked like an egg. Then after 18 months of typical development, what I call the autism bomb struck where there was a loss of functional communication. There were meltdowns. There was self-stimulatory behavior. In short, I became a very autistic little kid.
Now, in those days there was very little known about autism. It took my parents a full year to find a place for diagnosis. The questions still remain. Where does autism come from and what can we do about autism? As we look at autism and as we look at the increased prevalence rate, there's much debate as to whether these increased numbers, which seem to be delivered on a Federal Express truck daily, whether there really is more autism. Is it something we're doing to the environment? Is it something in the food we're eating? Is it something else? We even have some people who wonder if it's an evolutionary path that people are taking. Might it be that we're better at recognizing it?

Just as we look at that Federal Express logo, where some of you may have not noticed until now, that arrow between the E and the X. That arrow has always been there, it will always be there until they change their logo. Now that I've pointed it out, even if I take it away, the next time you see a Federal Express truck, you probably can't help but see that arrow. Just like I've increased your ability to diagnose white space arrows in Federal Express logos, maybe society is now better able to recognize autism when it sees it. Is it a combination of the both?

Anyway, what I want to get onto is the idea as we look at autism, some of us may consider it as a sort of bomb that strikes when we lose functional communication or for the other half of us, perhaps something's apparent at birth. I believe that with the technology we have, with the know-how that we have, with the techniques that we have, that people with autism leading fulfilling and productive lives can become the rule rather than the exception.

In that way, perhaps autism doesn't have to be a bomb at all, but perhaps autism can become, you might say, Da Bomb. How do we look at autism as becoming Da Bomb? In this case, in particular focusing on friendships, dating and relationships. Just like everybody else, relationships begin via common interests. The challenge we have is what can we do to move from parallel play to interactive play? A couple of examples I have, one of those
examples is what my parents did when they refuted the professionals' recommendations for institutionalization and implemented their own what we would now today refer to as an intensive home-based early intervention program, emphasizing music, movement, sensory integration, narration, and imitation.

At first, they tried to get me to imitate them. That didn't work. Then they imitated me. I think the important implication is that the prerequisite to getting good interactions with somebody on the autism spectrum, or actually anybody, you have to develop a trusting relationship with that individual, then you can move on. That is what we need to do for individuals on the autism spectrum, reaching into their world so that we can then pull them into ours and that we can mutually share our experiences. That goes with relationships, intimate relationships, dating, and sexuality as well.

Relationships start early. Relationships start in elementary school, even before then, but as we look at elementary school, it's really a matter of special interests. What special interests can we use to engage that individual with autism with others? For me, elementary school was very difficult. I was a social and academic catastrophe in elementary school. I didn't know how to interact with my classmates in a way they could understand. There was a lot of bullying. Teachers didn't quite know how to reach me. I would just spend my days in elementary school reading books on my favorite subjects, be it science, be it dinosaurs, electricity, aviation, whatever it might be. Sometimes I'd wonder if there was more to school than just reading on my favorite subjects. I think what that translates to is that teachers didn't quite know how to reach me, but since it wasn't a behavior problem they just left me to my own devices.

By the time I got to middle school, things had gotten better. Now middle school is a challenge for many people. You don't need to have autism to have difficulties in middle school. I think things were better for me because, number one, I figured out that using words instead of sound effects from the environment really helped with social interaction. I also was able to join the band, music being a special interest of mine. Now I had a
common interest with others, a structured activity, band rehearsal and that common subject of music to talk with my classmates.

That was when I began, you might say, to meaningfully interact with my classmates. I suppose if I had been interested in dating at that time, maybe I would have done it, but I wasn't interested then and nor was I in high school. Those classes based on interests, activities, clubs, we start seeing those in middle and high school and they can be a silver lining to what can often be this challenging situation.

Another challenge that we face in developing relationships is addressed in RDI, as developed by Steven Gutstein, and the idea that we're looking at developing skills and experience sharing interaction in addition to the skills that may already be present in instrumental interaction. The instrumental interactions, those are the ones that the interaction has a particular goal, when the goal is completed, the relationship is over. That might be a relationship you have with a cashier, a gas station attendant, or someone who paints your house. You may be very friendly with them, they may be friendly to you, but when the goal is reached, people part ways.

The experience sharing relationships are the ones that lean towards meaningful friendships, intimate relationships, and sexuality. This is something that's important to focus on and that requires an amount of co-regulation, being able to regulate yourself with others on the physical realm, emotional, and intellectual realms.

As we move on, here I am at age 10. I was awfully concerned with the letter E. I was concerned because when you drop E before adding ING, isn't that E going to get hurt? I just interpreted language very literally. I had a friend who said he felt like a pizza. He didn't look like one, he didn't smell like one, so there were some issues there as well. I remember about this time, sitting in a restaurant, I should say as a teenager, and my mother suddenly pointing somebody out a couple of booths down and saying, "She's giving you the eye." I interpreted that
literally and I didn't want her eye. I thought it was a disgusting thing to talk about while we're eating. Let her keep her eye and I'll keep mine and all of that. What I didn't understand is that that was you might say the code behind or the meaning behind those words was she was looking at me, she was interested in perhaps getting to know me better. Perhaps if I had said hello to her, she would have said hi to me and we might have become friends.

Anyway, moving on, we're jumping right into the subject of sexuality for individuals on the autism spectrum. There are a lot of unspoken rules or hidden curriculum in the area of dating and intimate relationships. It's that hidden curriculum that helps us decode what are known as idioms. In other words, the words don't mean exactly the intent. Nobody expects anybody to hold a door above their head, but it really means to open the door and to keep it open until they pass through.

Other areas of hidden curriculum include the men's room. In this case we have a situation of two guys in the men's room. Sam made a couple of mistakes. He came in second, he's looking at Bob, and he's too close. It's hidden curriculum like this that is discussed by Peter Gerhardt and by Brenda Myles and other colleagues who focus in this area, that people with autism have a difficult time with. The good news is that we can learn these things, but it requires direct instruction, whether it's through a visual schedule, it could be a power card or a social story or some other social narrative, a video modeling, a role-playing. These are ways that we can teach individuals with autism skills in these areas.

To that point, Dennis DeBbaudt and I have been working hard in putting together a video on autism and safe travel where we do look at those hidden curriculum rules, in this case related to travel for those on the autism spectrum who are traveling, but may not understand all the rules including that of the men's room.

We're moving on to friendship and dating. It's time to address some of the myths that people have regarding those on the autism
spectrum. As we look at the slide here, it's important to realize the diversity of interest in relationships, in dating, and sexuality. The types of sexuality are just as diverse in people on the autism spectrum as they are for the rest of the population. We're challenged with, "How can we help people on the autism spectrum deal with this important part of life?"

The challenge that those of us with autism face is that we are deprived of the greatest resource in this area which is interaction with typical classmates. Often we find people with autism, they either may be in a separate classroom or even a separate school, or even if they're included, perhaps even at 100% in a regular school system, there tends to be relatively less interaction between them and their typical peers outside of class. What that means is that while the interest may be high in a teenager on the autism spectrum, they're going to need education and it's up to us to provide that education.

What are some things we can do? If we look at the movie "Adam," this is a picture from the movie "Adam," which is a novel. It does well to depict the challenges a young adult on the autism spectrum experiences in terms of maintaining employment, he has to move out of his father's house who passed away, and with his girlfriend.

At this particular point, we're in a situation where we see Adam in a spacesuit. His girlfriend comes in and she is visibly very upset about something that happened in her life. In particular, her father had just been indicted in court for some sort of financial fraud and she's visibly looking upset. When she tells him his first question is, "Well, did he do it?" Perhaps someone more familiar with the hidden rules or unspoken rules of social interaction, perhaps the more appropriate thing to do would be to provide emotional support and give her a hug. His girlfriend fortunately has the presence of mind to literally ask him for a hug and he gives her a hug. He had no problem doing so, but in this case he just needed to be told.

Another question that many people with autism have relates to appropriate behavior. The recently released five-point scale for
social behavior for adults can be very helpful in this area. In other words, how do you know when you're stalking someone who you're interested in dating? Often the three strikes, you're out rule is pretty good to know and something that most people know intuitively. Again, somebody with autism may need direct instruction and this might be a good way to do it in terms of what might be considered stalking and what behaviors that a person with autism who's interested in dating someone might be interpreted or misinterpreted as stalking. Sometimes a little cognitive behavioral therapy can be helpful which involves rethinking our thinking, which is a good way to put it.

I know many on the autism spectrum who are pretty much panicked. They want to have a date, they think they need to have a date, they must have a date. What is an appropriate way to meet other people to go on dates and whether somebody is appropriate, whether it's appropriate to even ask somebody for a date?

We talked about the idea of building relationships through common interests and those relationships begin with friendships. As we look at the work of Teresa Bolick, there are some things that she covers that are important for everybody whether you have autism or not. These are the things that perhaps somebody with autism may need some direct instruction on, the idea of before getting to sex, how do we talk about closeness? What are some good listening skills that we need to have in order to be a good friend?

Hygiene is another challenge that many of us with autism face. I believe a lot of it has to do with sensory issues. What I mean by that is, for example, I know people on the autism spectrum who report that taking a shower is like standing under a hail of bullets because their skin is too sensitive. Well, there may be other ways that that person can get themselves clean and remain clean. Others may not know when it's time to take a shower, so perhaps we need a schedule, shower twice a day, morning and night, whether you need it or not. Other sensory-related hygiene challenges can be from soap. Some soap may be too smelly for some and others may need strong smelling soap in order to feel
like they're washing up.

Sharing life experiences, agreeing to disagree. These are some other areas. Disagreements are not blood sports and it's important to understand when it's time to say, "Okay, let's agree to disagree." How do we show interest in someone, showing interest asking them questions about their life, their interests, not monologuing which we tend to do about special interests, but sharing our time together?

Touch is important. It's important to understand that we don't touch our friends unless he or she says that it's all right. That leads into the concepts of appropriate and inappropriate touch. Some people refer to good and bad touch. Rather, I think it's clearer if we think about what's appropriate and what isn't appropriate.

Finally, it's vitally important for the person with autism, as it is for everybody else, to have a trusted adult that they can go to so that they can discuss things that are concerning. "Well, this person who I just met yesterday, she was touching me over here and I felt uncomfortable with that. Is that okay?" They won't fear being judged, but just being given good information.

A visual tool that can be helpful is using the circle of relationships. Let us say for example we have this person on the autism spectrum that perhaps for sensory reasons, hugs everybody they see. As a three-year-old, four-year-old, or five-year-old, this is a very cute thing to do and it's perfectly fine, but as the person reaches their teenage years, 20s, and beyond, it's much less appropriate. Perhaps it can be good to review whom it's appropriate to hug. You could probably always hug your family or significant other at any time, there are some friends who you can hug and others who you might not, and hugging a stranger is probably that's just something that it's is better not to do. There are many ways to teach these concepts. The circle of relationships is just one, but developing a power card or other social narrative can be helpful as well.
How do you know what level of friendship you're at with a particular person? Again, looking at the five-point scales can be very helpful in this area as we help to clearly define what we expect from someone who is a spouse or we have an intimate relationship with, a girlfriend, a friend, acquaintance, or a stranger.

There are many resources on friendship, dating, and relationships. One of the best ones, I think, is called "The Other Half of Asperger Syndrome. That's by Maxine Aston. We can think of it as an owner's manual. It's a little book. It costs about $10. There's great advice in there for helping those who are already or want to begin a relationship with somebody on the autism spectrum.

One piece of relationship information that I find particularly compelling is that perhaps we don't need to insist on eye contact when talking about emotional issues. Maybe instead of sitting face-to-face and insisting on eye contact, might it be more efficacious to sit side-by-side, maybe even sit facing away from each other, or talking in the dark? It's all kinds of wonderful advice like that, which this book can be helpful with.

Dating. Dating is a big challenge for many of us with autism. Dating probably has the greatest number of unspoken rules and hidden curriculum than just about any activity I can think of. What can we do to stack the deck in the favor of those of us on the autism spectrum? One is knowing where is the best place to develop relationships or to grow relationships. From what I find, a noisy bar, a singles' dance, anything where socialization is a primary goal is going to be really difficult for us, whereas, better venues may be gatherings based on interests where there's a readymade topic of conversation. Whatever that interest is, it could be trains, it could be astronomy, it could be animals in a zoo, whatever it is, there's usually a group of people who have the same interests. The question is what can we do to get that person with autism involved in that group?

The mysteries of dating. Dating can be very mysterious for a
lot of us whether we have autism or not. There are many cultural challenges we face, expectations as to who makes the initial effort of contact. Is it the male? Is it the female? Most people think that it is the male who makes the first contact, but research suggests that it may be the female who exhibits certain nonverbal cues that a male picks up and then walks over to the female. Anyway, it's these very subtle things that people with autism may have difficulty in picking up.

As we continue on, the most important thing is to find and develop the way that that person with autism is most comfortable in interacting with others. Support groups can be very helpful. Some of them are face to face. The Asperger's Syndrome Association, AANE, right outside of Boston can be very helpful. The Asperger's Association of New England, they have support groups in this area. There are others in New York and some in California such as AGUA that was started by Jerry Newport. There may be support groups online as well.

Another five-point scale can be helpful. A friendship scale. What can we do to make friends? What's appropriate? How can we rethink our thinking so that's it's easier for others to be friendly with us?

Here I am as an adult. I'm very fortunate to have met my wife. Even that wasn't easy. I remember my first experience with dating. I'm not sure if it was dating or not. I was in undergraduate school where after spending a lot of time with this lady, she suddenly told me that she loved backrubs and hugs. I thought, "Well, gee. That's pretty neat. I tend to seek deep pressure, hugs are fine with me, and I like backrubs a lot. Okay, if you're into that, then so am I." You might say I confused a potential girlfriend for a deep-pressure Temple Grandin squeeze machine.

While she was interested in hugs and backrubs, it became clear after some weeks that she was interested in a deeper relationship, which didn't occur to me until after a lot of discussion. I found out she thought she had been dating me for about a month. That made me realize that I needed to know more
information in this area. I spent hours reading texts on body language, relationships, dating, such as Autism for Dummies. The sheer numbers of these books suggested to me that maybe this is a challenge for people who don't necessarily who have autism and maybe all these books aren't just written for those of us on the autism spectrum.

By the time I got to graduate school, after spending a lot of time with another lady reviewing each other's homework, which morphed into doing things socially, she suddenly gave me a hug, a kiss, and held my hand at a beach very much like you see here. At that point, I had the social story down. If a woman hugs you, kisses you, and holds your hand all at about the same time, it probably means they want to be your girlfriend. That being the case, you'd better have an answer right away. It could either be yes, it could be no, or it could be further investigation and analysis as indicated.

Well, it seemed to be a good thing to do and now we've been married for just about 23 years. She has written about her experiences in my autobiography, "Beyond the Wall." As you can see, she is from the Far East. She's Chinese, to be specific. I think there are some more important implications there as well.

I remember as a child all of my friends being older than I was and then when I got into the world of work, it seemed like all of my friends were from other cultures. I think what that suggests is, also based on my discussions with others on the autism spectrum who have had similar experiences, that people of a given culture, they know intimately how you're supposed to behave, and those who behave differently, not many people want to have much to do with you. Additionally, differences in behavior may be misinterpreted as well. That's how things are done in America. Maybe people flap and jump up and down when they balance a worksheet on their computer.

Thirdly, perhaps the most important aspect is that people of other cultures have their own challenges integrating into society and may be more tolerant or perhaps even appreciative of differences. There's actually research, I believe, on Tony
Attwood’s website suggesting that the most successful long-term relationships for people on the autism spectrum are with those having differences, whether it’s cultural, age, ethnic, whatever it might be, neurocognitive. These relationships tend to be more successful.

I now spend most of my time in a sheltered workshop for people with Asperger’s syndrome where we spend days, sometimes years, perseverating on minute subjects. Sometimes social interaction between community members is not the greatest. Some people refer to this place as a university. If you want to see undiagnosed people on the autism spectrum, just check out your professors.

Moving on, what are some other helpful resources related to friendships, dating, and sexuality? Valerie Gaus wrote a great book based on cognitive behavioral therapy. It’s self-help book, but since this book is focused towards people on the autism spectrum, this can be very helpful. She’s a master at putting together worksheets and then help guide you to whatever you write on those worksheets mean to help you better understand yourself.

Here are a couple of other texts. Both of these are written by people on the autism spectrum. As we look at “Love, Sex & Long-Term Relationships,” Sarah Hendrickx, she did what nobody else had done before and that was to interview many people on the autism spectrum on what they wanted and expected from love, sex, and long-term relationships. I remember emailing back and forth with her and suggesting to her one time, and I don’t know what made me say this, but I said, “You really write like someone who has autism.” She said, “Wow, that’s interesting. Other people have told me too.” She then went to get an evaluation and found out indeed she was on the autism spectrum.

Jerry Newport, who I mentioned before, wrote a book with his wife who is also on the autism spectrum, "Autism - Asperger's & Sexuality." This book you might say, well, is coming from the horse’s mouth. He’s great for introducing concepts for those of us with autism or those of us who are supporting individuals with autism to then help them along. When do we talk about sex?
Jerry suggests just like with anybody else, look for signs of interest. Whether it's suggestive clothing, stickers, whatever it might be, signs of masturbation, this is great stuff to talk about for incidental teaching, and it's a life-long conversation. It's just not one sit-down conversation and you're all done, but it goes through life.

Keeping in mind that sex is normal, it's private, and it's clean. I'm not sure where people go the idea that sex was dirty. I remember watching the movie "Waterworld," and for any of you who watched it, with Kevin Costner, the best thing to say is that the water in that movie just looked filthy. I remember telling my mother about it and she said, "I watched that movie too and I didn't see any overt sexual activity." I told her, "No, that's not what I'm talking about. The water really is dirty. It's muddy and it makes you want to take a bath."

Moving on, it's important to discuss sex in a developmentally appropriate manner, not too much, not too little. Make sure you understand the questions being asked. That reminds me of a story I heard about a parent where their child asked them, "Where do I come from?" This is coming from a five-year-old. The mother is going through this long explanation into conception and sexuality and the child is very patiently waiting. Finally, she can't stand it anymore, she says, "No, my friend comes from Kalamazoo. Where do I come from?" It's important to understand the question being asked and to be able to explain things in a matter-of-fact manner.

Simple visual aids to help explain male and female anatomical functions. Those of us on the spectrum tend to be visual and the Jerry Newport book has some great visuals on that for that purpose. Sarah Attwood, that's Tony Attwood's wife, has another book that can be very helpful in this area. Sex is a part of growing up and there are proper places and times to discuss this topic. Also the importance of being responsible for your actions in seeking, having, and respecting the wishes of a potential partner.

Other areas of discussion are perhaps sharing your own
experiences as appropriate, what worked and what didn't work. Validating feelings of a possible fear of loneliness. Most importantly, it's your job or somebody's job that the person with autism has that they can go to for further questions or emergencies.

More material from Peter Gerhardt, keeping in mind as to what is appropriate versus what is private behavior. For example, masturbation is considered private behavior. The challenge to us is to make sure we communicate that to someone on the autism spectrum, or even not, who might have problems in determining when and where to engage in this activity. What is appropriate touch or inappropriate touch? What are all these body parts called anyway, both the formal name and the multiple slang names that everybody in school uses?

Keeping personal boundaries. We talked about masturbation. When is it appropriate? Where is it appropriate? How do we teach somebody with autism appropriate places to engage in this behavior? We've talked some about social skills in building relationships. Avoiding dangerous situations and abuse. I know many, and it's usually females, on the autism spectrum who have been horribly abused in relationships and in sexuality as well. Honing one's dating skills and just what are your responsibilities? For the individual transitioning into adulthood, the teenage, it's important for them to be able to identify where on their body it's appropriate to be touched or not touched when they're with someone who they have an intimate relationship with or not and to be able to have someone to talk to about this important subject.

A couple more books, "What's Happening to Me?" one for boys, one for girls, written by Alex Frith and Susan Meredith, respectively. These books were not written for people with autism or any other developmental or other disability, but they do very well in explaining what is happening to the body as we mature into adults. Helping individuals understand puberty, relationships, and sexuality, this is a great resource as well.

Moving on, getting back to masturbation, we may have people
with autism who, just to put it bluntly, don't know how to masturbate safely. While we take it for granted that everyone knows how to do this, it wasn't until I heard of this young man who decided that perhaps using a Coke bottle was a really good idea. Maybe it did feel like a good idea until they had to break it off his penis. It was pretty ugly and he needed education. We need to prevent these things from happening. The real challenge is how are we going to teach this and who is qualified to teach these things? How can we be comfortable in teaching these things? It may be apparent...

Minta: Stephen, if I may interrupt. I'm sorry. I want to say that ultimately comes down to the parent in explaining these things. I have so many questions from parents. Perhaps you've answered some of them already, but there are some very specific things that the audience would like to know. Can I open the floor up for questions?

Stephen: Yeah, you can open it up. I just have a... Let me check.

Minta: Do you need to wrap up? Do you want to wrap up and then we'll take questions?

Stephen: Yeah. Let me look at the wrap-up.

Minta: Oh, absolutely.

Stephen: Yeah, there are just a couple more slides. Let me wrap it up.

Minta: Sounds great.

Stephen: I know this is an important subject, so we'll wrap it up.

Minta: Absolutely. Go right ahead.

Stephen: All right. We've got a few more resources. These resources are videos developed by David Hingsburger, one for females and one for males, on how to masturbate. They're not pornographic. They're educational videos. It may be something that a person who has to teach somebody with autism how to engage in this
activity and then turns around and teaches it to them. Maybe somebody with autism would watch this under supervision and thus could learn these important skills.

Another book by Mary Wroble who asked the question, "What is my young son going to do when he reaches his teen years, puberty, and into adulthood in terms of what can I do to teach him how to take care of himself regarding hygiene, puberty, and sexual relationships?" It's written in very simple language. The language in this book is great for taking off the page and turning into a visual schedule, social story, power card, or whatever mode of communication is helpful to that individual.

What else do we have? Redirecting inappropriate masturbation. The reason why I show this slide is to emphasize that we have the tools in order to redirect behavior and to teach behavior. Now if I were to replace the word masturbation with something else, let's say hand flapping, then this would read pretty much the same way. We have the behavioral tools to modify behavior and to guide behavior. Again, it's just a matter of applying them.

Here's a nice curriculum on teaching relationships and sexual health for people on the autism spectrum from AAPC Publications. There's a teacher's manual and a DVD that can be very helpful as well.

Wrapping up, we're moving on to resources for friendships and dating. There's a number of books here which can be very helpful that can help guide those of us with autism as this whole conference focuses on helping those with autism be successful, being productive, and fulfilled. In this case, we're focusing on relationships and sexuality as we all move through our journey in life to be fulfilled, be productive, and to be successful.

On that note, I'm now showing a picture of my books. Some of them are in English and others are in other languages depending upon which language works best. I think now this is a great time to start taking questions.
Minta: Thank you so much, Stephen. This is such an interesting topic and we have many parents writing in. We have people with spouses with ASD writing in. Let's begin with Paloma from France. She's got a very interesting situation here. She says, "Hello, I was wondering if you could tell me how to go about a nine-year-old autistic boy who panics whenever he gets an erection? He starts yelling, crying, and throws himself on the floor while touching his genitals. I wish I could find a way to explain erections to him, but I have trouble getting through." Can you give some advice to Paloma?

Stephen: Yeah, I certainly can. Something like an erection happening, I think, would be pretty scary for someone who doesn't know what's going on. I think the best thing to do is to communicate to this nine-year-old boy. It might even be through a picture schedule. I don't know how verbal he is or how his communication skills are, but it could be through a picture schedule demonstrating what happens when a male gets an erection. In this picture schedule, having a picture of one, it may seem pornographic, but it is important to show what it looks like. Also the idea that after a period of time, it goes away and everything's the way that it was before. It's really using communication to prepare him for what happens, what the cycle is, you might say, and that it eventually goes away. He may be scared to death if this change has occurred and it's not going to go away.

Minta: Very good. Deepak Paul, or maybe it's Paul Deepak, from Abu Dhabi, he wants to know, and I'm paraphrasing it here, during adolescence and puberty, is it right or wrong to allow your child to masturbate in the bathroom?

Stephen: They're going to masturbate no matter what. However, the bathroom is not a good place to masturbate because those of us with autism, we may have difficulties in proper generalization. If one can masturbate in the bathroom at home, well what about the bathroom in the train station, in an airplane, at grandma's house, or at a friend's house? It's best to restrict this behavior to a place that is specifically that person's, and that's the bedroom. Your bedroom is always your bedroom. It's not your parent's bedroom, it's not your sister's bedroom, it's
not your aunt's bedroom, and in that way, making sure there is a place that is appropriate to engage in this behavior.

Another thing that is important to teach an individual is the rule of closed doors. A closed door means that you don't go in and you'll come back later. Well, sometimes you just have to talk to somebody and what do you do if you need to talk to somebody behind a closed door? You knock. Having a way to say, "Not right now, I'll be out later," or "Be right out, I'm busy now," just somehow communicating that they're not ready to talk at this particular moment is another important aspect.

Minta: Very good. That's a very good point about generalization. I'm so glad you brought that up. Sharon from Flushing, New York says, "My almost 13-year-old son who's on the spectrum as very high functioning is going through puberty and I don't know how to approach the subject of masturbation. I try to tell him that it's natural and nothing to be ashamed of, but that it's a private thing." I know you covered this topic, but just briefly, she wants to know, "Is there anything else I should be telling him?"

Stephen: I think it's just important to be open and to be available to him to talk to him about the subject whenever he feels the need to do so. It may be that if it seems more appropriate to have somebody else to talk to him about it, possibly a male figure that can be trusted, then that's a fine thing to do too.

Minta: That's very good advice. Now, Michelle Wilson from Carlsbad wants to know, and this is a very interesting question, "Can you please address how parents can help nonverbal adolescents with this issue?"

Stephen: That's a good question because people who are nonverbal also desire relationships and are sexual beings. What we need to do is just use the tools that we already have. That may involve picture schedules. I don't know if those Mayer-Johnson pictures related to sexuality and masturbation, but it might be possible to create these pictures in that style. In that way, communicate with the individual who is nonverbal. We're communicating with
them or we should communicate with them just as we communicate anything else to a nonverbal person.

Minta: Very good. On the other side of the spectrum here, children who are very verbal with boundary issues, Jennifer from Orlando says, "I have 17-year-old with ASD. We are having extreme issues with him understanding sexual boundaries. At the moment, most of his behaviors are of a verbal nature stating inappropriate comments, both publically as well as in the home. He will bluntly state what he's thinking and feeling and would like to do. I am pleased he's using his voice and having natural feelings, however, I need to find a way to get him to understand why his behaviors are inappropriate. An example of an inappropriate comment would be, 'Hey, mom, look at that woman's breasts. Don't they look good? Don't you want to touch them?' making the comments in the presence of the woman.

"To compound our issues, I am now a single mother and he has no male role models. Usually when correcting his behaviors he will state, "You just want me to be a female, but I am a male.""

Do you have any suggestions for her?

Stephen: It's a difficulty in generalization, or in some cases overgeneralization, of certain ideas. I think communicating to him through social stories, through power cards, being that he's very verbal, perhaps even using video. Let's role play it and video it correctly and video it incorrectly. Let's use YouTube and let's see if we can find videos of where people are acting appropriately and where people are acting inappropriately. Have discussions as to what's appropriate and what is inappropriate.

Minta: Very good. Kind of like a social story, maybe the mother can create a social story. Do you happen to know of any of that sort of resource?

Stephen: None come right off the top of my head, so it would probably be a matter of creating one.

Minta: Yes, I was thinking that too. Thank you. We have another
question. I don't see the person's name, but she says, I think it's a she, "My son is 14, hasn't shown any signs of sexuality at this time, but he doesn't understand space. When is the appropriate time to speak to him about it? For him, if you speak too soon, it would open a whole can of worms leading to issues that we didn't have before, so I don't want to bring it up too soon." How would this mother know when is the right time to bring it up?

Stephen: When she sees evidence of interest. What is some evidence of interest? It could have to do with clothing. It could have to do with magazines or books. She might notice him looking at women, whether it's in pictures or walking down the street, or masturbation. When she starts seeing him engage in these activities, that's a good time to talk about these things. If nothing else, it's also important to make sure that he's literate in terms of the parts of his body and what is appropriate to touch and what is appropriate for other people not to touch, because we also want to make sure that he remains safe from potential abuse.

Minta: Yes, of course. That's such a good point you bring up. We've talked a lot about male issues, but there are women of course, girls on the spectrum, and some mothers are concerned about how to approach the subject of puberty with their daughters. Laura Christensen of Rantoul, Illinois says, "My daughter is 10 years old. She has autism. She fears any kind of blood, bruises, etc. I'm sad to say I'm sad to say that I'm dreading the day she begins her monthly cycle. How can I help her and not stress us both out at the same time?"

Stephen: There are two books that come to mind. I don't know if the video is showing or not, but I've gone back to my slide that has images of the two books. From Usborne Press, "What's Happening to Me?" Getting the female version of that book by Susan Meredith will be great in explaining these things. The Mary Wroble book that I mentioned before, there's some good information in there as well to help her prepare for this monthly or regular event that just about all women go through.
Minta: Yes, very true. A lot of people here are older people and are talking about relationships of adults with ASD. Carol from Los Angeles says that many... I guess NT means non-typical. I see this a lot throughout the questions.

Stephen: It means neurotypical.

Minta: Neurotypical, oh.

Stephen: Yes. It's another way of saying normal.

Minta: That's even better. Who's normal anyway? Neurotypical I like much better.

Stephen: Well, yeah. That's another question.

Minta: Absolutely. Many neurotypicals feel the lack of emotional intimacy affects their desire for sex in their marriage. How can a spouse with ASD meet her needs?

Stephen: From what I've found, people with autism can be very emotionally intimate. I think where the challenge comes is that these expressions of emotion or intimacy may be expressed differently in those with autism. If you're not looking for that different expression, then it's very easy to miss it. What that really means is getting to know that individual on the autism spectrum.

Minta: Carol from Los Angeles has a few questions, so I'll just kind of paraphrase it. She's the one that asked about that question, but she's saying, for women, emotional intimacy and physically intimacy are tied and she wants some advice on how can we teach our teens and young adults how to respond compassionately and appropriately to a neurotypical girlfriend or spouse who requests and needs more emotional connection and emotional sharing. You covered that a little bit before, but can you tell us a little bit more about that?

Stephen: What that requires, at least in part, is becoming more aware and sensitive to one's own emotions. In some cases that may mean
building a visual scale or thermometer so the person can gauge their bodily reactions which might clue them into their emotional state. In other words, working from body reaction to determine emotional state, which is the reverse of what most people do since they have an emotional state and then they'll know how their body will react.

As I think about what people with autism can do to express their emotions and communications with those who don't have autism, it's also important to keep in mind that it's a two-way street. Those who don't have autism, it's good to develop a greater understanding of how those with autism do communicate. In other words, meeting halfway.

Minta: That's a good point. Now what if the person is an adult and doesn't know these unwritten rules? How would you teach these unwritten rules to adults that are just finding out or are in denial about their sexuality? What can a partner do to help them and teach them to deal with their denial?

Stephen: Denial's a very hard thing to get through. I think the most important thing is to approach it from a point of helping the person out. In other words, not focusing on the diagnosis, but focusing on the situation and perhaps pointing out... Say a person has trouble with monologuing about their favorite subjects and they're not giving the other person the chance to talk or changing subjects. Perhaps that person's partner could work out a nonverbal cue to communicate to that person with autism that it's time to give that other person a chance to talk.

Minta: Speaking of giving people a chance to talk, Stephen, I want to open the phone lines. If you are dialing in, you can ask a question to Stephen by raising your hand. You do that by pressing *2. If you're listening and you have a question for Stephen, just press *2 on your phone and I will see that you have a question and I will call on you. Let's hear from some people out in the audience. While we're doing that, we'll take another question here from the panel.
It seems like a lot of people are asking about preparing their children for marriage. I know that this is all very similarly related, but I want to make sure that everybody's concerns get addressed. Is there anything from a relationship point of view that a parent can talk about to their child who is about to get married, wants to get married, or is entering into a more permanent relationship like a marriage?

Stephen: It's a very broad topic. For someone who is perhaps engaged and about to get married, I would take it that that person has already developed a close a relationship with that other individual and that they've figured out ways to communicate effectively with each other. Probably the best thing to do is to, as with all couples, continue to work on effective communication in learning how to decode, you might say, emotional states of the other person or if it's difficult to decode these emotional states, just simply asking or checking in on a regular basis.

Minta: Very good. That's good advice. Miguel from San Diego has a question. He says, "I have a 17-year-old son who currently masturbates by putting his blanket between his legs and moving back and forth. Should we teach the correct way to do it or can he continue like that as long as it doesn't show inappropriate behavior?"

Stephen: I'm sure there's equal diversity in masturbation in people with autism as those who don't have autism. I think if the technique or approach that he's using isn't damaging anybody or anything and it's working for him, then I don't see any harm in continuing that way.

Minta: Absolutely. Again, callers, if you are dialing in, please press *2 to raise your hand and ask a question. While we're waiting for more questions to come in, Stephen, would you like to expand on a topic that we've discussed that comes to mind? Is there something that you would like to mention that you have not mentioned?

Stephen: I think the most important thing in regards to relationships,
intimate relationships or otherwise, is for the individual with autism, just as all of us, we need to find ways that we're comfortable in interacting. Some people like to go to bars and interact that way. Others like to do very different types of activities. Whatever that activity is, one can't say is better than the other, but we can say that a particular activity or method might be better for a specific person than another. It's really a matter of finding out or determining what works. I can't tell if we got disconnected or not because it seems very quiet.

Minta: Oh, I'm so sorry. I had mute on and I didn't know. I was saying Carol from Los Angeles is asking another question. Carol if you are listening, if you were dialing in, you could ask Stephen your question directly. You have a lot of questions and it seems maybe you have a spouse with ASD. If you want to talk to Stephen directly, you can just dial *2. That might be the best way since you do have so many questions and I would love to get your questions answered. If you would like to call in, that would be great, and you could talk to Stephen yourself by raising your hand by pressing *2. If not, I can put these two questions together.

Carol from Los Angeles would like to know, and I will put both of these questions together and see if you can address that, how can you teach a spouse with ASD to agree to disagree when they don't have perspective taking skills? They get defensive, argue, or shut down, but then they get angry when they're asked about their emotional state. The person is getting angry and getting angry about being asked being angry. What do you do in that situation?

Stephen: I think what that suggests is finding ways to help that individual become more literate in their own emotional states. Perhaps that might even mean spending some time watching videos of people in different emotional states, happy, sad angry or otherwise. Also, especially with anger because anger tends to be the most unpredictable emotion for people on the autism spectrum and hardest for them to deal with, it also could be a good idea to find someone who's an expert in this area, a counselor. I can
think of plenty here on Long Island. Carol's calling from the other end of the country, but I'm sure there are people there who can help in this area as well.

Minta: I'm sure. A question comes to mind while we're talking about this. Do you feel like a person with ASD, like in this case it would be who Carol is speaking about who gets angry, defensive, shuts down and then gets angry about being asked about that, in your opinion, I know it's individual, but with a person on the spectrum, generally, would a sense of humor help to diffuse the situation or do you think it might ignite it more?

Stephen: It depends on the individual because we have some people in the autism spectrum who are very good at decoding humor and understanding what it is. Then there are others who are just totally bewildered by humor. I think that mirrors the general population except with autism things tend to get exaggerated, so it's to a greater extreme. It depends on the individual.

Minta: Absolutely. Some people who are writing in are having difficulty dealing with the schools. I don't know the person's name, but the person is asking, why is it so difficult to have school address health sex-ed with teens on the spectrum? Is there a good curriculum to suggest to the school? Another person had asked, what would be a good way to approach the school? It's kind of the same question. How can you deal with the school to talk about these issues and deal with these issues with children on the spectrum?

Stephen: I find that in many cases reluctance of a school system to deal with any challenge, it could be sex education or it could be something else, often results from a lack of knowledge or resources in these areas. According to the individuals of the disabilities education act, these are not supposed to be barriers for proper education of people with disabilities, autism or otherwise, but reality rears its ugly head and it often is.

For the school system, one thing I would recommend is getting it
written into the IEP because the IEP is a legal document. Once it's written and signed, that's what has to be followed. Secondly, a very good curriculum, as I mentioned in my presentation, is titled "Intimate Relationships and Sexual Health." That can be found either from Amazon.com or from AAPC Publications.

Minta: Fantastic. Thank you for that helpful suggestion. Jennifer from Orlando would like to know, "With an individual on the spectrum, they often observe their parents as well as the community for appropriate instruction on how to behave. How would you combat the issue of inappropriate media outlets such as TV when instructing a child on appropriate boundaries? My 17-year-old often refers to shows he has seen on how to behave and refuses to listen to my explanation on inappropriateness."

Stephen: The shows on TV where there's a lot of inappropriate behavior, these can be great starting points for incidental teaching and the fact that just because something is on TV doesn't mean that it's appropriate. There are a lot of inappropriate things that we see in media. It's probably what drives up ratings, but they can also be good at helping us describe what isn't appropriate in looking at what isn't, contrasting appropriate behavior and inappropriate behavior.

Minta: That's a good point. I know we covered this a little bit before and perhaps it's the same answer, but Monica from Pasadena wants to know, "How do you help a low functioning teen with autism who cognitively doesn't understand the concept?" It just says, "the concept." I imagine of sexuality.

Stephen: For those who are nonverbal, being nonverbal doesn't necessarily correlate to a person's awareness of their environment, their receptive language, or even intellectual ability. What we need to do is we need to return to those tools that we use to teach anything to a nonverbal child, whether it's the day schedule, whether it's the routine for getting out of bed, washing and having breakfast, or it's the school schedule and we need to apply these to relationships and sexuality. Perhaps these are the places where we engaged in masturbation
Minta: Very good. I have some parents who are asking questions about how adolescents and teens on the spectrum relate to one another sexually. This is about, I guess, social interactions as well. Sharon from Flushing comments, "I guess a parent would have to know when their child was ready if he or she was on the spectrum or not." Good point. "My question is, since social interaction is an area that they work on, do those on the spectrum talk to one another about it?"

Stephen: Yeah, we do. Sharon from Flushing, she would only have to go to the GRASP website to see that there are people at GRASP, Global and Regional Asperger's Syndrome Partnership, that we do talk about these things amongst each other.

Minta: Good. Of course. There is a mother here who has three children, Laura Christensen from Rantoul, Illinois, and this is a very interesting question. She says, "Two of my three children have been diagnosed with autism. I suspect my oldest does too. They're only connection biologically is me. They each have three different fathers. I have ADD and other 'issues.' Is it possible that I have it also? How can I go about looking into this?" I guess what she's saying is, how would I know if I'm autistic?

Stephen: She would go find a clinician, a neuropsychologist who is familiar with autism as it presents itself in adults. There are a number of people who can do that. As for finding someone in her specific area, I would suggest going to the local chapter of the autism society and asking this very same question for direction to a qualified professional.

Minta: Yes, of course. I guess there's no real questionnaire, "Are you autistic?"

Stephen: There are some questionnaires that are known as screening tools. There's one by Simon Baron-Cohen, which I think is called the Autism Quotient, and there's another one by Edward Ritvo. It has a number of questions and you answer them. It's like ticking off boxes on a computer and then it will score it up for you.
What it does is, it doesn't diagnose you, you can't be diagnosed just on a simple instrument like that, but what it will do is provide a suggestion as to whether it may be appropriate to seek further information about it.

Minta: Yeah. I think that'd probably be a good jumping-off point. If I may interject here. It's a spectrum disorder and I have met other people who told me that they have autistic tendencies and that's what I tell them. We all have those like tapping a pen, chewing on something, there's always something, some repetitive behavior that people use to self-soothe. It is a big spectrum so I just wanted to say that. That might be a helpful tool for her to begin to... ADD, I don't know if you speak about that, but is ADD considered to be on the spectrum?

Stephen: That's a good question. The way most people look at ADD is that it's part of a larger spectrum that includes autism. What that means is that there are a number of ADD characteristics that overlap with autism. However, they're not one in the same.

Minta: Very good. We have just about eight more minutes here. I want to remind you if you are dialing in, please press *2 and you can ask a question directly to Stephen. This is a very interesting topic and there are not very many specialists on this who have such an insider's point of view. Stephen, this is such a great opportunity for people on the spectrum to call up and ask you questions. Parents with adult children with autism, please call up and ask Stephen questions by pressing *2.

We are not getting in any new questions so can you just tell us some more about... Let's see. Some people find this to be a very taboo situation. Cheryl from San Jose finds the topic to be very taboo to talk about. Aside from schools, how could she get other support organizations to be willing to help address talking to her son? I imagine to her son or educating her son, it is a taboo subject. Is there anything that you could suggest that might just put people more at easy about talking about sex?

Stephen: I think the important thing to keep in mind is that it's a very natural activity that just about all adults engage in and that
these people are going to engage in sex no matter what, whether they're told about it or not. Most of their behaviors are instinctual. People figure it out. However, the more we can do to educate people in safe sex, especially for those who have cognitive developmental disabilities, it's really all about their safety.

Minta: That brings to mind another interesting point about contraception and talking again about safe sex. Do you have any advice for parents on how they might address that? Either a parent or somebody who's in a relationship with somebody on ASD, what would be a good way to go about talking about contraceptives?

Stephen: Contraceptives, how to use contraceptives, I think it's just a matter of going back to what we would teach anybody else. What would you do to teach your typical daughter or son about safe sex and using contraceptives? Then the question is how would you modify that teaching so the person with autism can get the same understanding?

Minta: I can hear your sink running Stephen.

Stephen: Yeah, I had a little bit of dinner.

Minta: Thank you. We have less than five minutes, so if there are people in the audience out there that are listening that have ASD, I know you spoke a little bit about this before, but maybe you can give a little bit more advice about how would an adult with ASD, what would be a good way for people with ASD who are interested in having a relationship to meet one another? You mentioned about something on the computer before.

Stephen: I think the best way to meet others, and it isn't necessary that someone on the autism spectrum should be dating someone who has autism, but I think it's more about just meeting people. How we can meet people, again, it's how we are most comfortable in meeting others. What do we like to do? For example, if I was interested in dating in high school, all of the bicycle rides and the clubs that I engaged in that involved bicycle riding,
that probably would have been a good way to meet people.

Minta: Very good advice.

Stephen: We're already doing an activity that we're interested in. There's less emphasis on all of the social stuff that goes along with dating that perhaps we find in more socially oriented activities and we already have something in common to talk about.

Minta: That's a fantastic suggestion. Thank you so much for that.

Stephen: You're welcome.

Minta: We have a very good question here. I don't know the person's name, but they want to know, "How do you address gay relationships to those on the spectrum?" I'm not sure if they mean how do you address if the person is gay or if their parents are gay, but how would you go about addressing gay relationships to people on the spectrum?

Stephen: I would address teaching gay relationships or about them the same way that I would teach it to anybody else, that there are different types of sexuality or however you want to categorize them, and that while it appears that most people tend to be heterosexual, in other words, attracted to the opposite sex, there are some others who are attracted to people of the same sex. It isn't something to be ashamed of. This is something that, at least the best science we have, is something that is innate to the individual. In other words, there isn't anything you can do to make a person gay or to stop them from being gay, but that's who they are. Then the questions is how can they be the best person they can be as they are?

Minta: Very good. We have time for about one more question. Joanne from San Diego asks, "My adult daughter on the spectrum is in an independent long-term relationship. How do I make sure it is a healthy relationship without being overbearing? Do I ask her ILS worker, social workers, or just keep my eyes out for anything out of the ordinary?" In other words, I guess she's
asking if there's a red flag. What advice could you give Joanne?

Stephen: This is her daughter?

Minta: Yes, her adult daughter is in an independent long-term relationship. She wants to make sure it's a healthy relationship without being overbearing, without being, I guess, herself, without being overbearing. She must have some concerns that it's not a healthy relationship. What can she do?

Stephen: Invite them to dinner. Get to know them.

Minta: Good idea.

Stephen: Find a way to do some stuff together. Not so much as parent and child, the parent can never be a peer, but perhaps moving somewhat in that direction.

Minta: That's great advice. Now she's asking, should she also consult with her ILS worker or her daughter's social worker? Do you think that that would be an appropriate thing for her to do?

Stephen: One of the aspects of being a social worker is making sure the client, or I think they're called consumers now which is a horrible sounding word, is safe, is happy, and is not in a dangerous situation. It's perfectly fine to discuss with the social worker these concerns.

Minta: Very good. I still have time for one more quick question and it has to be a quick answer. Debbie wants to know what was the biggest breakthrough for you to get where you are today?

Stephen: That's a hard question to answer because I can't think of any particular one thing, but it's more a series of small realizations that occur from time to time where I suddenly become aware of particular situations in my interactions with others. I can't think of one day I woke up and suddenly everything changed, but it's all been a gradual process.

Minta: Absolutely. I guess it's that way for all of us. Thank
you. We are just about out of time. Stephen, I want to thank you so much for your time and insight for being with us today. Thank you so much for being here with us. Thank you again.

Stephen: Oh, my pleasure. I look forward to the next time we come together.

Minta: It was fantastic. I look forward just to speaking with you again. It was such a great topic. Thanks again. Thank all of you out there who participated in our webinar and asked such great questions. We will hear from you back in an hour. Thank you, Stephen. Bye-bye.

Stephen: You're welcome.

Minta: Take care.