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Marriage and Autism

What you need to know.

Dr. Robert Naseef

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Textual Transcription of marriage.mp3

Speakers: Ernest Priestly
Dr. Robert Naseef

Summary: In this web-based conference call, Ernest Priestly discusses the effects which raising autistic children can have on marriages and other domestic relationships. His guest, Dr. Robert Naseef, offers expert advice to listeners, discussing how to strengthen and maintain a marriage or relationship where an autistic child is involved, dealing with the attitudes of family members and friends, explaining disabilities to children themselves, and choosing the best course of treatment for your child.

Full text below.

Ernest Priestly: OK, everyone. I want to thank you for attending our sixth conference call that we've had in the past 35 days. We are very fortunate to have with us Dr. Naseef, who is a psychologist and independent practice owner in Philadelphia. He is a consultant in numerous schools and service organizations, and he has a broad background of experience in both education and psychology. He is a native Philadelphian – go Eagles! – and a graduate of Temple University, and he serves on the Board of Directors in the Center for Autistic Children. *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability* was his first book, and he received local and national recognition.

He's also been heard on national public radio, and one of the questions we would get from many of you as we had our conference calls was "can we get some people here to talk to us about how autism affects relationships?" Now, the statistics kind of vary but the consensus seems to be that over 80% of marriages who have children with autism typically go through a divorce. And that's a very stark statistic and I think that what many of you have asked for is "can we talk to somebody that can help us with strategies that we can use to help better, or strengthen our relationships with our families?" And so that's why we've brought here Dr. Robert Naseef.

We're lucky to have him today, and he's going to give us a talk about autism in relationships and families. Maybe you can start off by talking about your book; I think people would be very interested in picking up a copy of that.

Dr. Naseef: Hi everyone. I wrote a book about family life that's based somewhat on my experiences as the parent of a child with autism. He's 29 this fall. It's based on my experiences both as a parent and as a psychologist. It's called *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability* and that focuses on a broad range of conditions – autism being one of them. I've also co-edited a book called *Voices from the Spectrum* which is a collection of sixty essays about autism written by parents, grandparents, teachers, doctors, people with autism, brothers and sisters of kids with autism; so a really broad range of viewpoints - *Voices from the Spectrum*.

So you can go to *Amazon.com*, put in my name – Robert Naseef – and my books will come up. I also have a website that's called *AleternativeChoices.com* and on the website there's various articles, and if you go to the page on the website that's called *Special Families*, you can sign up for my newsletter which comes out roughly monthly, and I rate articles about autism and other disabilities, how they impact families, what people can do to cope, and I answer people's questions, and that sort of thing. So, if tonight's discussion is something that you'd like to continue, the newsletter is a way that I keep in touch with people and keep bringing information and resources about family life to people.

So, as I mentioned, I have an adult child with autism so I've been living the life you've been living for almost longer than I can remember. Sometimes it seems like yesterday and sometimes it seems like a lifetime ago. So tonight, especially based on what Ernest was saying, we're going to talk about how autism impacts the marriage and the family as a whole. Ernest started by giving this off-putting statistic of an 80% divorce rate. Now, there's something kind of interesting going on in the world around us. Recently, I went on *Google* and I put *autism* in, because I know people are just flooded with information, and can't get off the internet, and can't make heads or tails of it. And 26 million pages come up when you put the word *autism* in, so where do you start? Hard to know, and hard to know what information is reliable. There's a lot of myths out there on various topics, autism included. So then I went to *Amazon* and I thought "well, anybody can make a webpage but not anybody can write a book", so I put *autism* in the *Amazon* search engine and 17 thousand books came up. Again, where do you start? I think we need people with expertise, people we can rely on and trust in our communities and our schools, that we can turn to, to help us sort things out.

In my work as a psychologist I try to provide that to people. I see myself somewhat as an interpreter between the parent world and the professional world, because I live in both. This statistic – I'll just start with this, since Ernest brought it up – of the 80% divorce rate is one of the myths. However, you go on the internet and it's on many, many websites, however this is no source for this statistic. There has never been any research that confirms this. But what is true? The divorce rate in our country is 50% for first marriages, and that's startling enough. It appears that the divorce rate for families of kids with autism and other disabilities is roughly the same. From studies which have been done over the years, they're generally inconclusive and generally don't find a higher divorce rate – certainly nothing convincing, particularly with autism. We certainly need more research in this, but I just would want to disabuse you from that notion that 80% of your marriages are going to end in divorce. At least half will, and I myself have been divorced and re-married, and many people I know have been divorced and re-married. There's a lot of great step-parents in the autism community, as well as there is in society as a whole.

But what is true? It is true that families raising kids with autism are under incredible stress, that their stress rates are higher than the general population. That's true. And sometimes that's the last straw for folks. And if you're in a minority group, if you're economically disadvantaged, that just makes it all the much harder – racism, poverty, single parent families – it makes it just that much harder. But, we don't need to so much walk in fear that 80% of us are going to go through a divorce. I think what is reflects, though, that people are under stress and worried about breaking up. So about 50% of first marriages fail, and interestingly about 70% of second marriages end in divorce. The main reason given for that is that in second marriages, we're often talking about step families – both people or one or the other bringing in kids from a previous marriage, and that's more complicated to balance – being a step-parent and being a biological parent – so second marriages have a much higher divorce rate than first marriages.

If you take all marriages together, first, second and third, about 57% end in divorce. And as I said, there's more reported marital distress among families of children with special needs, autism included. There's a high rate of depression amongst moms of kids with autism. I would think that's true but there are no studies on that which I can find at the moment. So why does the myth exist? I think because people want to have a reason for how bad they feel or how afraid they are and maybe want to say "autism is so awful, our families are breaking up" and maybe this provides some basis for getting support. But exaggerating the negative doesn't help us cope – it's hard enough. So what I want to hopefully do tonight is help folks get a grip on what can help your relationship, and what positive is going on in your life and how you can build on that.

So that's my introduction, and maybe we can just get into some questions and discussion. I don't want to talk too long and miss talking about what's most important to you.

Ernest: Okay. I have a question, and that is people, as you mentioned, are under stress, and there's just so much going on with these families. How do parents cope? If you had a list of, say, five things that parents could use to cope, what would those five things be? Let's say a husband, a wife and a child, and if there were five things we could do to help us cope, what would they be? I mean, I guess it varies for everyone but --

Dr. Naseef: Well, it does. You know, there are definitely things I could recommend. People that are satisfied with their marriages, that are happy with their spouses, they generally consider each other best friends. And friends enjoy doing things together. When autism enters the picture, people often – and understandably – get obsessed with the autism and are out of balance in terms of the family as a whole and the relationship. So one of the best things you can do is finding some time to spend with your spouse, doing things you enjoy together, and of course this can be hard to do – it can be hard to get a babysitter, hard to go out for an evening – so I urge people to just start wherever you can. Figure out where you can steal some time for each other. It could be an at-home date, watching a video after the kids are in bed, or just sharing a glass of wine or a cup of tea – but find time to spend with each other. Take a walk around the block after the kids leave on the school bus, or whenever you can. See when you can spend a little time with each other – it doesn't have to be a formal date, although it could be. That would be number one – spend some time together.

And think about taking care of yourself, a little bit. The strain of this is tremendous, and actually men are better at taking a break than women, and I guess if a lot of women are listening, you know this! Guys will take a break to go out and play golf or a little football game, they will take a break, and moms have a harder time doing that. But if you can get a break, whether that's a little exercise after the kids leave for school, or some journaling, or a few minutes reading the paper – just some time to relax. Almost any form of exercise will help, especially if you can do it together - taking a walk, riding a bike.

And you know, especially with autism, we learn a lot about behaviour modification and reinforcing the positives. One of the best things couples can do – and all couples, not just parents of kids with autism – is let your partner know what they're doing right.

Ernest: I liked the way you said that; say that again.

Dr. Naseef: Catch your partner doing something right. Remember why you're together – people are together because they enjoy each other, they have common interests. Catch your partner doing something right. This is the best help of all in just renewing your relationship and coping with the many things that we have to face. I think that's about three or four – I can give some more.

Ernerst: Yeah, you had three – take a break, catch your partner doing something right, and the other one was find some time for each other.

Dr. Naseef: Do you want a few more?

Ernest: No, that's fine – those are good topics, and I know one of the questions that I received earlier, too, was about the dynamic. You may have one child who has autism, and the other children might now, and how that dynamic creates stress on the mom, because the other kids are asking "why is she spending more time with the child who has autism" and not as much with them. I know that question's come up several times in previous conference calls, and I thought you could maybe discuss that, too, because it does happen quite a bit.

Dr. Naseef: Sure. That's a big part of what goes on in families, and if we just kind of step back from the issue just for a moment, it's really impossible to give equal time to children of various ages, abilities, and interests. And that's in any family. The youngest is usually, and appropriately, getting more attention. The child with autism, even if they're chronologically the oldest, is often developmentally younger. So that child is, in effect, going to hog the parents' attention. In fact, one of my daughters wrote an essay that's in the *Voices from the Spectrum* book in which she called my son *dad hogger*. And when I quote from this essay at lectures and presentations I give people, they crack up because, from it kind of (from a kid's point of view) says it all – the kid with autism is hogging the attention from the parent. Why? Because that kid might not know danger, be able to verbalize well or might have numerous problems. And it's totally necessary, but what is possible is to give each child some special attention and to meet their needs as best as possible. Again, there are some tips and coping strategies I could give you on this.

It's really great to have a play day regularly with your typically developing child. It's also great to talk about what's going on – get children's books on autism (there's a lot of them now) – but talk about it openly, be able to listen to your kids' grievances about it, and give them some special attention, whatever that might be. That goes a long way towards helping to have balance in the family and avoiding problems that might come up. If the typically developing sibling feels left out and doesn't seem to have a voice, that child may develop a symptom because that's the only way to get attention. So we want to avoid that by giving each child some special attention, and explaining – let's say the child with autism is Billy – that Billy's brain is different, Billy needs to go to speech therapy, Billy needs a special class, et cetera, et cetera, but you have needs too and we're going to make sure those needs get met. Just that sort of special outlook on each child can bring about a very different dynamic as opposed to that child always having to wait and there's just not enough to go around.

Ernest: Very good, that will certainly help a lot of people here who have heard that, because it's a very prevalent problem and I get that question all the time. I'm glad you answered it. So let's see here, for those of you that are on the call, please post some questions – we have our doctor here to answer our questions and we definitely want you to post some more as time goes on here. There's some great information, I'm sure. Also, as you may have heard before, we wanted to know how many of you have children below the age of three. The other one was how many had been between elementary school, middle school and high school.

So those of you listening online, just post that information so we can see it, so we get an idea of who's in the room with us, here. Let's see here. Here we have one question from Angie in Prior (I'm not sure what state that is) – the question is "how do you help your other children understand autism, and in my case, OCD. My oldest is fourteen and has ADHD, and my son is 4 and has autism, OCD and many other problems".

Dr Naseef: Okay. How do you help children understand autism, OCD and other things? I think it's sort of like helping children understand sex. By that I mean we need to give them information at their level. We need to answer questions that come up, explain differences, and sort of keep it simple. Children who grow up well-adjusted, whether they have autism, OCD or are the typical siblings, they are better adjusted when they were just always given information, were always informed of what was going on. So, as I mentioned a little while ago, there's a lot of good kids' books about autism – *"Andy and his Yellow Frisbee", "Russell is Extra Special"* are a couple, but there's a growing number. Public libraries have them and schools have them. There didn't used to be much of this but there's a decent supply of kids' books, and another one I really love is called *"All Cats have Asperger's Syndrome"*. That book uses the behaviour of cats to help children and adults understand behaviour in autism. So if you think of a cat and how they come to you when they want you, and prefer to be alone a lot of the time. It's a beautifully illustrated book from Jessica Kingsley Publishers in the United Kingdom, and it's also a coffee-table type book, with a lot of very cute coloured pictures of cats, but it's actually a good book to help adults understand autism.

I have one grandma in her practice raising her grandson with autism, and she bought ten copies and gave them to all her relatives. She had been given magazine articles and journal articles and stuff from the school… I don't know if they were reading it but they certainly weren't getting it. When she saw this book in my office (*"All Cats have Asperger's"*) she got that, and people seemed to understand it and click in. One dad I counselled recently was perplexed about whether he should tell his son with high-functioning autism that he has it. The little boy was asking a lot of questions, like "why do I have a special aide in school", "why do I have to do this and why do I have to go to occupational therapy", and I said "sure, tell him". He was nervous to tell him, but he saw this book in my office, and he got himself a copy of *All Cats have Asperger's*. He left it lying around at home, and his some came to him one night and said "Dad, I think I have Asperger's". So kids really can pick up on this. The key is to talk with them at their level, giving them information they can digest, that's sensible to them.

Same thing with OCD; there's some kids' books about that. I don't have the titles off the top of my head, but again they're pretty readily available. Just go to *Amazon* and put in *children's books about obsessive compulsive disorder* – you'll get a couple of titles. You won't get a hundred titles, you'll get three or four, and your library may have them. Often, OCD occurs simultaneously with autism, so you're not alone in that situation. Hopefully I covered that question; I don't want to go on too long.

Ernest: Yeah, I think you did. As a matter of fact, we've got a couple more here that I've got in. We have one comment from a woman named Catherine who says "I love hearing about the *All Cats have Asperger's* because I've often said my son is a perfectly good cat, not a defective dog, because people who respect him are so cat-like."

Dr. Naseef: That's great. It's actually not a unique concept; it's been around for a while. I have a friend who has Asperger's who loves my cats, and says "you know, I'm a cat!" It's an interesting, creative and insightful way to understand it. "Our kids are not defective dogs." And a lot of dogs have ADD, by the way!

Ernest: That's correct. I have a couple of golden retrievers who are that way.

Dr. Naseef: Especially when they're young, right?

Ernest: Definitely. I have a question here from Debbie in Georgia: "Do you have a suggestion for parents who don't agree on the course of treatment for a special needs child. If one parent checks out the other ends up doing everything. How do we even it out without creating friction?"

Dr. Naseef: It's a little hard for me to answer in a general way.

Ernest: That's got to come up, because we had one person here, we had shown them the diagnosis and they're still not even on the same page as me. That's gotta be a struggle for people.

Dr. Naseef: I think I can talk about it in a general way. People – moms, dads, men and women – are still different individuals and are not necessarily developing their understanding at the same rate. Quite frankly, men are a little slower with this. It's really hard for us as men – and actually I've written about this extensively in my book; there's a chapter just about the psychology of fathers in *Special Children, Challenged Parents*, and often I'll get men who don't like to read to read just that chapter as a standalone one – but for men it's really hard to talk about things we can't fix. We feel powerless; we want to fix the problem – not that women don't - but women are much more able to talk about things they can't fix and to get comfort from it. Men get upset talking about things we can't fix, and we want to shout down.

Ernest: Men are kind of like “we want to win; we want to be a winner”.

Dr. Naseef: Right! I’m not proud of it, Ernest, but it is true in a general way. So men are on a little different trajectory with this, a different course. But on the inside, I find, in the work I do, how people really think and feel deep inside is relatively the same – men and women. So, really important, I think, to also pay attention to the relationship part. Where that comes in is that often the mom dives into this, and that’s natural – nobody can do a better job diving in with all that has to be done – but often the father feels left out and outside the loop. One of the things I’ve been able to do sometimes with couples is talk about this, and ask the one who’s less involved – and sometimes it’s the mother, where there’s a stay-at-home dad, or a dad who’s working nights and during the day is more involved. But I’ll ask the one who’s less involved “is there one area here you could take over, and give your partner a little breathing space?”

For example, one dad I know decided he would do research on sensory issues because he saw his son was really sensitive to sound, and shut down in noisy situations. So he sort of became a mini-expert on how to reduce the sound in his son’s environment, and played a role in the IP meetings and other things. The mom still did the lion’s share, but the dad developed a piece he could contribute to. Men want to be given something to do that makes a difference, so often if you want to get your husband more involved, give him a specific thing, because we want to win, we want to fix, and make a difference. But we don’t tend to understand how this is all working, but if you give us a specific thing to do, that will help us stand up to the play and be a more active partner. That’s one way I approach that.

Ernest: Okay, well that’s good, because I think that gives them a certain degree of ownership. As a matter of fact, I was listening to someone talk about how men want to be winners, in that way they take ownership of a sports team. You know, if you’re an Eagles fan, I’m a Pittsburgh Steelers fan, for example, and you get in there – you want to take ownership, to be a winner and to be a part of it. The fact that the wife gave him something to do, to contribute, I’m sure made him feel really, really good. It’s like a touchdown pass – it’s like “I was there to make the play that won the game.”

Let’s see here – let me get a couple more questions.

Dr. Naseef: I can probably just give a bit of information. There’s one website on the whole world wide web that’s devoted exclusively to fathers of children with special needs. That’s *FathersNetwork.org* – it comes out of Seattle, Washington. That’s a really excellent resource about getting fathers involved, with many essays by fathers. Many fathers with kids with autism have written for that website, so I’d highly recommend that. You’ll see an essay or two of mine there, but it’s a great website for, about and by dads, and the only one so focused.

Ernest: Let’s see here. Here’s a question here from Adrienne, and her question is “what do you do when your husband disagrees on how to handle tantrums?” I know tantrums are a common problem, and you can have two people who disagree with how it’s done.

Dr. Naseef: Often you need an objective person to talk to. Again, sometimes you end up in a power struggle, and everybody’s losing, really. There is a science to this. There are strategies which are proving more effective, but a lot of times if people just can’t agree or read something or have the same sense of it, it’s good to get an objective point of view. That could be the child’s teacher, speech therapists or professionals working with the child who have time to sit down with you, or a mental health professional who has experience with this sort of thing. Or a school parent’s support group – there’s a lot of ways, but often you need an outside voice to say “this is what’s proven effective”, whether it’s tantrums or other behavioural problems.

Often, couples become polarized, with one being more hopeful, one being more discouraged, and people just get kind of stuck. It's understandable. Sometimes you just need an objective or outside point of view. You have to be really careful with tantrums, because sometimes in our zeal to get the tantrum over with, we're actually providing a lot of the tension and reinforcing it. It's not always really obvious, how to handle tantrums or kids fighting each other. It's not always so obvious. Our sense of justice often gets in the way – "this is right and this is wrong" – it gets in the way of couples solving a problem, that sense of knowing what's right. It's not that you both have to think or act exactly the same way, but it is important to have some common understanding on how to handle the big issues.

Ernest: I have one question here which will probably echo with a lot of people here. They chose to use the name *Worried*, from Chicago, and it is: "It seems impossible to manage a special needs child or two, with two full-time careers, a marriage and a household. Something has to give – how do people do it?"

Dr. Naseef: Oh, boy. She or he sounds exhausted. It is hard. Two full-time jobs is very hard. It can be done, I think it requires other support. I know some people who do that, who have a part-time or full-time nanny, extra help in the home, or somebody like the grandparents who lives-in with them. They have more support. What frequently happens is a mom who is praying to go back to work ends up not going back, or only working part-time, or getting her job scaled down a little bit. A dad, similarly, might stay home for a while, take some family leave or get a different job that allows more flexibility. So, there's a lot of ways that people do it, but it is exceedingly hard. Really important – you might not have a lot of time to care of yourself or each other, but steal a few minutes here and there. It's really important to try and have same balance, because basically our kids need us to be energetic and positive, and if we're worn down we're not giving them that important emotional tool that they need to grow.

Ernest: We've got a question here from a woman from San Francisco, and she asks: "Any relationship strategies for an adult with Asperger's who is contemplating marriage?"

Dr. Naseef: Well, again, this is an interesting area where, increasingly lately, there's a whole bunch of books coming out by people who have Asperger's, or work with it. There's a really good website – I'll speak on the issue but I want to tell about the website – it's *Aspires-Relationships.com.* This is a great website that's dedicated to people with Asperger's syndrome. As partners or individuals, it's a wonderful resource about relationships with people with Asperger's. They review books about Asperger's, and have articles there – one of my articles is there – but it's a nice website to be in touch with.

Basically, the things that all relationships need people with Asperger's need. What's more challenging is that what is often intuitive to so-called neuro-typical people is like learning a foreign language to somebody with Asperger's. The hardest thing is understanding how other people see you, and what the other person's point of view is. But it's learnable, but more like learning a foreign language than flying by the seat of your pants. Many of us do that and screw a lot of things up, too! But I would use this website as a resource – there are some online support groups on the *Yahoo! Groups* page, and if people want to email me through my website, I have some other resources, links and what not, but this is one of my favourite ones.

I'll tell you one more. It's a website for people with Asperger's and it doesn't focus on relationships, although it includes a lot of helpful information. It's called *GRASP.org* – which stands for *Global and Regional Asperger's Syndrome Partnership.* It's a national organization which has support groups in many cities – when you go to the website you can find the groups near you. People of all ages with Asperger's go to these meetings – usually monthly in a lot of areas – and they're very useful. You can get hooked up through your local *GRASP* chapter with other resources in your area for people with Asperger's. So *GRASP* is definitely an organization I think very positive in our community, and a good one to be in touch with. Loads of links on the GRASP website.

Ernest: *GRASP.org* – good deal. I have another comment here, a woman whose name is *Overwhelmed*, actually, from Detroit. She had a comment: “I would like to comment on the question *how do you do it?* I work two to three days a week, usually just four hours. My husband works full time. We have no family support” – that is, I guess, someone to take care of the children – “My *ASD* child is six years old, and I have one four year old. I do all medical research, and schools, so it’s hard to keep it together. At the end of the day I don’t have anything to give to my spouse. I’m worn out and also say something has to give. Most men feel their part in this is taking care of the finances. Do you have any comments about the latter?”

Dr. Naseef: Most men do sort of dive into trying to make more money, feeling like that’s the way they can contribute. So I think your view of that is pretty accurate. That’s where men often feel we can make a difference, and we can’t make a difference another way. Let me talk about one of the elephants in the room – nobody’s asking about this, specifically, but I think it’s a pretty big factor for a lot of families. Having a child with autism definitely subtracts from the marriage, and everybody’s tired and edgy. It’s not unusual; more common. The autism, as opposed to being romantic, is like an anti-aphrodisiac. In general, men may need sex to feel closer, to feel better, and to cheer up. While on the other hand, women generally want to feel closer in order to feel romantic and sexual. So we’re coming at this from different places. That’s why I called it the elephant in the room – it’s going on in a lot of relationships. The man wishing for more time, sex and romance; the woman too overwhelmed and wanting to feel taken care of, and closer, in order to once again feel romantic and sexual. That’s why it’s really important to find even five or ten minutes to spend with each other whenever you can. Try to make your relationship rewarding again. There’s really no substitute for that.

And yes, this is exceedingly difficult. Often I talk to people about this and say “take care of yourself – you need it, your kid needs you to take care of yourself.” They hear it like I’m giving them something else to do. They’re like “oh my God, now I have that to do! I have OT, PT, speech, special needs softball, and now you’re telling me to exercise and spend time without my spouse?! I’m going to fall apart. I can’t do it.”

People are really overwhelmed, but spending a little time taking care of the relationship can really help with these other things. It can really help people work together better. The loss of intimacy – and by that, I don’t mean sex, but closeness, real sharing. The loss of intimacy when you’re trying to raise a child with this disability is huge, and it just needs to be attended to a little. It’s like a plant that needs water.

Ernest: You mentioned loss of intimacy, being closer, and I’m assuming, too, you mean communication; each person talking about how they feel about what’s going on, and being able to disclose that openly and to be heard. That’s what I hear in what you’re saying, and I admit it’s hard to do that.

Dr. Naseef: It’s really hard, but I think our families need us to. I think that’s one of the challenges, and I think for myself that’s probably the biggest thing I learned, that my son needed me to do that, and I needed me to do it. I had to get past not being able to talk about my upsets. Often when I get just a small group of men together and ask them to tell their stories, it all pours out. At *FathersNetwork.org*, they put out a couple of short videos that are just interviews with dads, which are so compelling, and which men and women can relate to. They’re very reasonably priced, so I’d recommend those sorts of things.

Fathers need role models of other men who can be open, and see that by being open you’re not being weak. The male point of view often is “if I talk about my upsets I’m being weak, and I have to be strong for my family", meaning hold it in. But actually, often our families need us to open up and stop pretending that we can handle it, when really we're not handling it very well – we're just holding it in.

Ernest: Sure. Well, I want to say you've gotten a few *amens* from the people posting here. I wish you could see it – they're popping up here – a few people are saying "amen, thank you for this conference". Particularly one woman – I won't give her name or location – she has said that in her marriage she had a similar problem. In fact, her husband had cheated once, in large part, I guess, because what had been going on, and they've gotten past that, and have done what you said which is make time for each other and learning how to communicate better, and now their life is back to where it once was.

Dr. Naseef: That's great to hear.

Ernest: It is. People really want to talk about this – as a matter of fact, we've had about ten more questions in the last minute here.

Dr. Naseef: Good, that hit a nerve! I really think that's been in the closet of a lot of families. And you know, couples who have kids with autism have all the same problems that other couples have – on top of the autism! We are regular people, with exceptional things to deal with.

Ernest: Okay. We have one question here: "I have a son who has autism, who is five in pre-school. I'm in a new relationship and do not know how to keep it healthy. I wonder how to keep a healthy balance." An open-ended comment, not necessarily a question – but she's in a relationship with someone, she has a child who has autism, and clearly she might be feeling that this might cause an issue with her current relationship. I guess she wants to know what to do. I guess the other person has to know the differences here, and what might be involved with them when the relationship grows.

Dr. Naseef: Right. Well, I think you're in a good situation; I'd encourage you. Because if you are in a relationship with somebody who knows this child has autism and who cares for you, and is getting involved with you, then that's just really helpful. There are a lot of great step-parents in our autism community, as I mentioned a little earlier, if you were on the line. I would say your new partner or new boyfriend, I'm sure, wants to help. See how he wants to help. Take it slow, because it's overwhelming, but often a new partner can be a great support. That was certainly true for me – my wife, Cindy, certainly helped me accept my son's disability. She was more objective than I was, she could see it more clearly; she didn't feel guilty. So this can often work out great but I'd say take it slow and steady. Pay attention to the relationship; don't view it as something which is going to help you with your son's autism – do what you would do otherwise. I'd wish you well, and there's no reason why it can't work. It's a challenge, but it's workable.

Ernest: Good. Let's see here. We have one woman from Pittsburgh, and I'll try to decipher her question. She says she has a friend who has a child with autism, and the mom is involved with the child's life, but the dad isn't. The dad is a behavioural specialist but he's not teaching – how can I help her?

Dr. Naseef: I'll try to give a straight answer – you're concerned about your friend. Just say "I'm concerned about you; is there a way I can be helpful, or be of service? Let me know. I care." Just simply that. You don't have to fix it, or have any answers, but people really appreciate that. She might say to you "sometimes I just need a break", and then, if you can, watch her kid for a couple of hours. Let her go shopping, get her hair done or see a movie. But just say "how can I help? How can I be of service? I care." That will feel so great to your friend.

Ernest: I have another question here, which is: "How can I help my husband to accept the fact that our kids have the diagnosis of autism? How can I help him get involved? I really feel he has let the responsibility rest on my shoulders. I have a hard time meeting his needs of intimacy when he is not meeting my needs of getting involved, and the kids' needs."

Dr. Naseef: That certainly is a dilemma. It's a little hard to answer in terms of specifics, because I don't know the people. It depends on the age of the kids, and she's talking about two kids with autism. That's just almost unimaginable, yet so real, and I do know a lot of families like this. Sometimes just getting to the core of things – and I know these aren't the kids you dreamed of, and it's breaking your heart, and his – but sometimes I'll look a man right in the eye and say "this isn't the kid you wanted, and I know that." And that just helps him to open up. It isn't the kid either one of you wanted; I'm sure you love them nonetheless, and maybe more. But try to go right to the heart if you can. My philosophy of working with families is I try to just start where people are – where each individual is. He may really just be overwhelmed, and wishing he could handle this better. Again, you might need an objective person to talk to, you might want to print something out from the *FathersNetwork* website and leave it around, if you think it will speak to him. But catch him doing something right – tell him what you appreciate about him, even if he's working more to pay these bills, let him know what you appreciate. That also breaks the ice.

Ernest: I'm glad you said that; catching your mate doing something right. I know, as a husband with a newborn baby boy… I work at home, so I spend a lot of time with him. The other day, my wife said "honey, I just want to thank you for taking care of the baby today, and making sure he was washed and all those things". And just to hear that, although I know I'm supposed to do it, the fact that she said it and appreciates it goes a long way. It really does. It makes you feel alive, like you can push your chest out, so I can only imagine what it's like when families are going through this. You go into all these details, but it does really get attention, and does really help. I can attest to that.

We have another question, here. A woman who asked: "My marriage has already ended. What recommendations or suggestions do you have for beginning again with a spectrum high-functioning child, who is twenty years old but will not be placed outside the home for residential care?"

A similar response to the previous caller, I think.

Dr. Naseef: Right, but it doesn't sound like she's in a relationship, but is hoping to be. I would say just by being open and honest is the way to start. And young people with autism can be very endearing, and a lot of people can really enjoy somebody with autism, or high-functioning autism, but obviously you're looking for somebody who's compatible with you and compatible with your now adult – or virtually adult – child. It's a little more complicated. However, in the age of the internet, you could put out here who you are and what your life's about, and what kind of person you're looking for. It's amazing how people find each other now. It's much easier, actually, in some ways, to find somebody who meets certain criteria. Those without autism, who understands it, who either grew up with autism, worked in schools or whatever! So I think by being honest, you can start again, and you can live a full life. I really believe that. Not that it's easy, but it's really possible – and not far out.

Ernest: Someone has just given me a comment to repeat the information on *FathersNetwork* again – it's *FathersNetwork.org*. That's got the information on the fathers, some of the videos are on there where they interview fathers, and talk about what their experience is like with children with special needs. That's a good resource, and I'm definitely sure people are going to pick that one up.

Dr. Naseef: It also lists fathers' support groups, various ones around the country, so people may find local contacts there, too. Although it's a Washington state website, it has a lot of national resources.

Ernest: We have another person here whose nickname is *Power of Praise* from California. Their comment was, "One learns about the constant praise that children on the spectrum, and even neuro-typical kids get. We like what you said about how adults can use the praise tool, too – some more than others". So that's a pretty good comment.

Dr. Naseef: Sure, we all want that – who doesn't want that? Here's place I can put in another tip in terms of women who want to create some better communication and their partners are having listening, or talking. I learned this from my wife and my teenage daughters. They will say to me "dad, just listen – you don't have to do anything. I just need you to listen". So if you relieve us – and by us I mean men – of that idea that we have to do something about what you're saying, it makes it easier for us to listen. So I coach women to tell them to just listen, to say "that's all I need. I'll love it if I can just talk to you about this – just listen." That will often let him listen, and don't have to do anything. And then, couple that and tell him if there is something you can do that's useful to you – "I just need a break sometimes" – he'll probably do it. But if you just want him to listen all the time, that's too frustrating. But tell him "you don't have to do anything – I need to vent, to just talk about this. If you just listen, I'll feel better." And where there is something he can actually do, that you'll feel better about, tell him what that is. Tell him "I just need a break for fifteen minutes – I'll love you for that". And if you can get some of those things working, you'll feel better.

Ernest: We have another person here who says "Bingo! He hit the nail on the head with that statement." We have one more question, it's more of a question regarding how to diagnose or evaluate something. I'll ask it, and you can determine if you can answer it. The question is, "How can you determine if it is Asperger's or just high-function autism?" I guess that's for a doctor.

Dr. Naseef: Here's the thing. Tony Atwood – who's probably the one of the eminent authorities in the world on this – says, "Tongue in cheek, the difference between a high-functioning autism and Asperger's is the spelling." So, there's often not much of a difference. I mean, I could talk to you about it, but frankly there's not much of a difference when we talk about the autism spectrum. What we're referring to, however, is that with Asperger's the language is pretty spontaneous, intelligence is normal or above, and the primary problem is social. There's not a lot of the other sorts of symptoms – little to none – but it's primarily social. Kids and aults with autism learn and develop through their lifetime, so they're often becoming less symptomatic and moving along the spectrum. Stephen Sure, for example, who's a friend and colleague of mine, was non-verbal at four, and this past year got his doctorate in special education, and next year will be a professor of special education. And he was non-verbal at four, and kind of developed all the way through the spectrum to Asperger's. It's kind of a fluid diagnosis, but we're certainly looking for very good language skills, and normal to above intelligence for high functioning autism and Asperger's. But with Asperger's, little to no other symptoms other than social skills. That's the simplest answer I could give – but don't get hung up on it; it's not that important.

Ernest: Another question here from New York – they've just joined the call. They have a question here, in a comment. It says, "My husband does not believe our son has ADD and OS. He fights me constantly and basically undoes everything I try to accomplish with my son. It has been very frustrating and causes a lot of resentment that our children feel. He thinks my son just needs to mature. He is very mild but there are issues to content with. I feel as if I'm alone in this, am angry and contemplating divorce, but I'm afraid how my children will handle this. Any suggestion on how to open up? He will not even read the description of PDD-NOS, and unfortunately the arguing between us is terrible, and still upsets my son continuously."

Dr. Naseef: That’s a lot. I’m going to talk about this but I’m going to suggest that the person with this question gets some professional guidance. You clearly want to keep your family together, and it may really help to get a third party in there who can look at this with you and give you suggestions based on your personality, even if your husband won’t go. I would certainly stop fighting about the diagnosis and just focus on what you can do together to help your kid. I have the general belief that parents love their kids and want to help them, and when there’s a disagreement like this I just try to focus on “what do we need to do to help our kid?” Sometimes, many times, fathers take longer to wrap their minds around this, because we can’t fix it, it’s hard to understand, et cetera. Some of the best-adjusted fathers told me they started out the same way. I said to one guy, “how did you change, how did you go from a guy who couldn’t be bothered talking about it, to being so involved?” He said, “My wife had a relative who died in the west, and she went to the funeral. I was alone with the kids. In those three days, I saw what her life was like, and I changed.” So sometimes, the intervention is to go out for a while, leave them alone with the kids. Don’t do all the work – sometimes that’s very powerful. But again, I don’t know you or your situation; that might not be the right move for you, but it’s definitely worth it to work on the marriage and try to find a way to stay together. It’s not always possible.
I always tell people in this kind of situation that it’s better to try too long and too hard than to walk away and wish you’d tried harder. If you walk away, and think there’s nothing else you can do, and you think “maybe I stayed in the marriage a year or two too long”, you won’t be guilty. But if you blow it up and walk away without getting help or without trying, you might be haunted by guilt the rest of your life. I would say, try to get some help – talk to your doctor, priest, rabbi or minister, someone who could refer you or help you.

Ernest: I wanted to talk about something here which will probably be another conference call, some other time. We had a couple of comments from people here recently that are asking about autism and insurance. Are you familiar with what’s happening in that particular arena? A number of states are trying to produce initiatives and laws which will come into affect, allowing people to cover certain therapies through insurance.

Dr. Naseef: There’s definitely a whole movement around this. Pennsylvania just passed a law in the end of the spring session, that doesn’t go into effect until next year. There’s definitely a movement afoot for this – there’s certainly federal proposals. I would say, without becoming overtly political, to go to the websites of the presidential candidates and read their autism proposals. Both candidates list their autism proposals, what they support, et cetera. Just go to the websites, put in *autism* and you’ll see what’s going on with that. The important thing is not just the support of it, but the funding of it. Whether that’s insurance, or increased services, or medical coverage for kids on the spectrum – the important thing is not just supporting the concept, but supporting the funding for the concept.

Ernest: That brings us to another question – I have one question here that’s from a mom who asked this: she has a son with autism who is five years old, and he hasn’t asked about how he is different from other kids yet, but her daughter says in front of him how he doesn’t look at her, and doesn’t want to play a lot. She wants to know when is a good time to tell him – how should she tell him what’s different about him?

Dr. Naseef: Well, it’s hard to answer without knowing more about him, but as soon as he’s old enough to understand it. As soon as you can see him noticing it. It’s certainly time to be talking to the daughter about it. It’s never too soon to start talking openly and differently, like “Billy’s different. He doesn’t look into people’s eyes the way you do; his brain is different.” Just in really general ways. And again, it helps to talk to somebody who knows the child, because they know cognitive level, what he understands. See what his teacher thinks. Look at the *Cats have Asperger’s Syndrome* book. It’s really an individual question based on when can your child understand it, and that’s kind of a guideline to keep in your head. But for your daughter who’s talking about it, that means she’s old enough for you to be talking to her about it. She's noticing and she needs validation, to know that yes, this is difficult – sometimes for her – but she definitely needs you to talk to here. He will at some point, if not now. He may be in a smaller class, and wonder why, or may not notice or care, and it's not time to talk to him. But I'd ask my teacher and other professionals who are working with him.

Ernest: We have one question from a woman who is in a situation – she has in-laws who do not believe in autism. She has four children, three of whom are neuro-typical and one with autism, and the in-laws feel that this is not true. This has caused a strain on the relationship between her and her husband, and she wants to know what to do. It's a tough question to answer but I figured maybe you could point to her some resources which could help her out, or how to take a stance on something like this.

Dr. Naseef: Families are different – I don't know why they don't believe it, and neither do you. There's a lot we have to accept about autism – not just our kids' condition, but there's a lot we have to accept. One of those things is that not everybody accepts it – and people only get it when they get it. Often, the people who spend most time around your kids are the ones who get it, and those who spend the least time don't get it. It's a hard thing to believe, and to wrap your mind around it, and it's good to try to maintain compassion for people who can't wrap their mind around it, because once upon a time that was all of us. Once upon a time, none of us understood this, and it was hard. Sometimes it just takes time. Some people come around, some don't. That's just part of the life we have as parents. Try not to fight about it with your spouse – it's not like there's a good family versus a bad family – that's an argument couples get into with or without argument, and it's not a good argument. "Your family's crazier than mine!"

Ernest: There's one on every block!

Dr. Naseef: That's a good way to put it! The other piece of this, and it's sort of like when I talked about people's sex lives being the elephant in the room. Another elephant in the room is the genetic issue. Autism is a genetic disorder, and where it exists, there's genes often on both sides that just kind of collided, and there's other – if not autistic – people, quirky people, with mental illness, who exist within the extended family, and nobody wants to believe the genes came from them. So part of not believing it may also be a fear, either unspoken or unconscious, that the genes couldn't have come from our side – how can these people have produced this kid? It's not on account of us. So it's not really possible to change other people. All we have power over, in my view, is our own relationships. So I would, just try to go on, not get caught up in this argument because it will only bring you hardship and suffering.

Ernest: Got you. Okay. I wanted to put up another question here, and that is from someone here who says she's from Little Rock. Her question is, "What is the best way to discipline a child with high-functioning autism? Nothing seems to work." She tries to call him on something he's done but five minutes later he doesn't understand why he's in trouble. This is kind of a generic kind of question, but how does one discipline a child? I know it's a tough question for you to answer, because each child's different and you don't know them.

Dr. Naseef: Right. I can't say "how do you discipline your child?" but I would agree that every child is different and we have to understand them. On this question of high-functioning autism – and we talked about this a little before – some people think that because a child is verbal, that they have high-functioning autism. That's not necessarily true. High-functioning autism is also with the child's cognitive level. Is their intelligence or achievement average or above? That's what we're generally talking about. So a child can be very verbal, talking a lot, but not really understanding certain rules. They might be very impulsive or compulsive but are not able to follow certain rules. So the key thing we have to understand with discipline is that it has to be based on who the child is, and their needs. The child may not understand as much as you think, and the behaviour may have a meaning that eludes you at present. This is another situation where it's really good to get a behavioural specialist involved, to analyze the behaviour and help figure out what are good strategies, based on your child, based on what strategies are comfortable for you, on what your child understands and what he doesn't. Often, with any child (even a typical child), we keep trying the same thing, thinking it will work, and it's not. We need another point of view.

Freud's definition of *neurosis* – which is worth thinking about, not that I'm a Freudian – is doing the same thing over and over again but expecting a different result. So if you're doing this, and it's not working, back up. Realize it's not working, and get a different point of view. Get some help with this. I think you can make progress.

Ernest: Could you talk to us a little bit about your practice – what you do? I'm sure a lot of people out there have many more questions after they find out what your speciality is. For those of you who haven't posted a question yet, please do, as we have him here for another 39 minutes. But can you talk to us a little more about what you do, and what your specialities are, so people get an idea of what to ask?

Dr. Naseef: Sure. What I specialise in are the family issues around autism and other disabilities – how it affects couples, typically developing children, and that sort of thing. I work with some teenagers and adults with Asperger's and high-functioning autism. We also have other therapists in the practice who work with families; my partner and wife, Dr. Arielle, works with parents. We have therapists who work with children. We do diagnostic evaluations and second opinions, to help people who either need a diagnosis to get services, or who want another opinion because they're not sure it's autism, or they want a more in-depth look at the level of it – that sort of thing. A wide variety of services around the special needs issues, and families. As I mentioned at the beginning, we have a website: *AlternativeChoices.com*. If you go to the *Special Families* page and sign up for the newsletter I do monthly for these issues. My books are available on *Amazon.com.*

Ernest: Great. I'm going to send an email out, actually, after the call, so I can look up your book and include the link in there so they can purchase it.

Dr. Naseef: Great.

Ernest: That gives people an idea here – I have a total of 57 questions, but most of those are comments. So once again, everyone, if you have a question, this is the time to get it in.

We have one woman here who commented from New York, and she said there's a lot of talk about curing autism, and seems to feel this gives parents a kind of false hope. Her concern, also, is why there is such a growth in autism in girls.

Dr. Naseef: Okay. That's a really interesting question, and I'll talk about both of these. It used to be, just a few years ago, scientists thought autism existed on about 12-15 genes, and that the genes were triggered by either stresses in the environment or toxins. And we don't have a cure, and a cure's not even close because there's so many genes involved. With something like cystic fibrosis, there's one genes involved, and scientists believe that there will be a cure within a decade, because of the advancement in genetic intervention and other sorts of things that I don't understand entirely, but there's one gene involved.

With autism, there's many genes involved, making a cure very far away, if not impossible. A lot of the leading scientists view autism as more of a cancer-like condition, in the sense that there's many of them, and you need different approaches for different kinds. But early on, who wouldn't want a cure, and if there was a cure, I'd be in line with everybody else – I could tell you that. It's not like I'm expecting it, from my knowledge of this.

Now, why is there an increase among girls? I'm glad to hear it, and I'll tell you why. Girls, in general, when they have mental and emotional problems, it's more inner. With boys, it comes out in their behaviour. So girls, on the spectrum, have a slightly different profile, and are often overlooked and not diagnosed because they don't present the same behavioural challenges. Recently, I went to a seminar given by a psychologist from Australia, who reported that they were diagnosing almost equal numbers of teenagers with high-functioning autism and Asperger's, because here it's seven or eight to one, boys to girls. What the difference is in Australia, because they've basically socialised medicine, every kid is getting screened, so they're identifying more girls. So if we improve our system of early diagnosis and intervention – and it has been improving – we will identify more girls. It's not so much that all of a sudden more girls have it, it's that we're identifying the girls and helping them. But we're still way behind on that and in special ed in general, girls are unrepresented; not diagnosed nearly as much as they should be because their problems tend to be more inner than outer – a little less behavioural in general.

There are also few, but good, books about girls and autism. So again if you go to *Amazon*, put in *girls and autism*, it's a small but growing list, with really interesting essays and discussion about how this looks different.

Ernest: Sure. I have one more question here – Susan who, actually, is from Indian. She's listening online, and that's the beauty of this thing here, that we can talk to people all over the world. She has an issue with her mother-in-law who says negative things about her four-year-old child in front of him. She's figuring out how to address this issue with her.

Dr. Naseef: Wow. My solution would be to say "stop it!" but I guess there's a much more eloquent way of making the other person empathise, and stop doing that, in a way which doesn't offend them. Of course you want your mother-in-law to stop, and she may be embarrassed by your child's behaviour, or might not understand it. But one way you might approach this is to say that he needs to hear positive things from you. Kids with autism, like all kids, need our support, love and encouragement, and so she's finding his behaviour unacceptable, and wants it to be different. I'd try to tell her the way to help him to be different is to be positive, accept him as he is, and help him grow. That's as simple as I'd put it, and I'd be gentle but persistent in saying this. I know it upsets you – this is your child, and it is your job to protect him and help him grow. Your mother-in-law also deserves respect but not at the expense of your child, so I'd urge you not to be silent, but diplomatically as you can, ask her to be positive with your child.

Ernest: We have another question here. People are coming on the call a little later. This may have been answered before, but maybe you could repeat it if it has. It is: "If it's not already answered, what do you feel can strengthen the marriage?" And I think you mentioned three things: take a break, catch your partner doing something right and praise them, and of course, spend more time together between the two of you.

Dr. Naseef: Right. We talked about those things – I'll just add a little too it that I meant to bring up before. Sometimes people will finally get a little time and all they talk about is their child with autism because it's been such a challenge. So I would say take breaks from talking about autism, because it's consuming. Take a break, have some fun, even if it's just a ten minute walk, sharing a cup of tea, or if you can, going on a date. If you can't go out for a date, have an in-home date. Sometimes you can even have a babysitter upstairs with the kids, and you can have a nice dinner. There's a lot of creative ways couples can spend time together – do activities together you like, but don't give up on the marriage and don't neglect the marriage. The marriage is the glue that holds the family together.

Ernest: It sure is. Well let's see – we're up to 71 questions and comments.

Dr. Naseef: That's great. You know, another point: often in marriage, when we have a kid, we have to accept who a kid really is. It's usually not the kid we dreamed of, in some form or another. Even the most gifted or typical kid is not the one we dreamed of, it's a real person. And when we get married, we expect our partner to meet our needs – but then, we have a real partner. We have to accept the real person and what it's really like with each other. So that's the other thing that's going on in every house that would be going on whether you had a kid with autism or not. You're spending these years together, finding each other's strengths and weaknesses, learning about each other and often having to accept things that we wish weren't true. That's going on in every marriage, and the autism compounds it.

But one thing that really helps is the people that get through it and are happy – often they just stay committed. They don't solve every problem, but they get through it because they stay committed. I'd definitely encourage you to look at it that way.

Ernest: We have a couple more questions that have come in. One person asks – it might put you on the spot here – "What are the three reasons why you think couples who have children with autism divorce?"

Dr. Naseef: I think they divorce for the same reasons other couples divorce.

Ernest: You mentioned the pressure, of course, and all the other things on top of what most couples have. I guess, money is one…

Dr. Naseef: Money, sex and power! The things people fight about. What they disagree about, or are in conflict about – they're the big three. You know, an interesting website about marriage in general is *Gottman.com*. John Gottman is at the University of Washington in Seattle, and is one of the world's leading researchers on marriage and divorce. He developed a way that he could spend time with a couple and pretty accurately predict whether they would divorce or not. Here's some of this findings – you can look it up on his website.

Ernest: It's like a multiple choice test, right?

Dr. Naseef: Yes, he has some things like that. The marriages where people are critical of each other – and he differentiates between a complaint and being critical, putting each other down – have a high risk of divorce. A high risk of divorce where people are critical. He's got a whole system there, and he studied hundreds or thousands of couples, and can predict marriages that are likely to fail. And I'm oversimplifying it, but the negativity of people toward each other is the primary thing which breaks them up. I'd highly recommend his books about marriage – John Gottman – and I'll look up a title or two while we're talking.

Another book I would recommend about marriage which is really good is called *Grown-up Marriage* by Judith Viorst. Some of you might recognise her – she also writes children's books. She wrote this book, and talks about marriages which make it and those which don't, and the qualities that they have. Here's the important thing – the negativity, being mean to each other, a little over-simplified – is the reason people break up. The reason people stay together and find happiness in the long-term is, they are best buddies, and research shows this over and over again. The people who are married a long time and are happy called each other their best friends.

Here's the title of one of the Gottman books – *The Seven Principles for Making Marriage Work*. He approaches it from the positive point of view, and of course does show you that the marriages that don't have some of these qualities are the ones at risk. You can read a lot of it on his website *Gottman.com* for free.

And I have a chapter in my book (*Special Children, Challenged Parents*) on some of the things that couples need, and discusses in more detail some of the things we've talked about tonight.

Ernest: Tell me about what motivated you to write that book. Clearly, you deal with patients all the time but tell me how you got started.

Dr. Naseef: My interest in this started with my son's autism. He's going to be 29 now, and there's wasn't really much available in the way of help for parents, and I was in graduate school at the time; I was a school teacher. I decided I wanted to find out what helps parents when they have a child with a disability, so that's what I studied for my doctoral research. I interviewed families – not who were falling apart, but were coping well – to see what they were doing, how they were caring for their child, how they were taking care of their other kids, how their marriage was working. And that's how I started out. Then I begain speaking to groups of parents, at conferences, and that sort of thing. Sharing what I learned, and in my practice, providing counselling to families going through this as well as general psychological services, but as time has gone on, most of my time is now spent with families of children with special needs, in particular mostly autism, although other conditions as well. The dynamics are largely the same, while the conditions may be different. The impact on couples, on the siblings, et cetera, are similar. So I kind of became an interpreter between the professional world and the parent world. While this was going on, my son's autism was very severe. He doesn't speak, write or read, and he's really required a lifetime in care, so certainly, I've kind of paid my dues that way. There's not too much people can tell me that horrifies me, so I became good at listening about how people sort this stuff out.

Ernest: Got you. And if you, too, could address the issue of a much older child – because most of the people who call in here typically have kids who are younger – but what's involved with the care of your son? How did you plan this out, and what things do you think you should do? For the parents of children with severe autism, what plans should they start making while they're still young.

Dr. Naseef: Well, there's a wide range of possibilities. It's hard to know early on. Of course we all want our kids to grow up, be independent, marry if possible, go to college if possible, have a good job. We want the best for them, but we don't know what's possible. And so learning to kind of live with the uncertainty is what we all have to work with, and it's the same as with typically developing children. We don't know who they're going to grow up to be. That being said, when the autism is more severe – and you might know this by the time your child's eight or nine, if the child is going to need a lifetime of care – it's worth looking into what's going on in your state; what's available. This is all developing as we speak.

My son is in a group home in the county we live in, and goes to a day program. It's not what I ever would have dreamed of for him, but he lives in a very nice home, which used be a rural area (though it's becoming suburban now). He gets three hot meals a day, and goes to the day program where he does some simple vocational things, and recreational things (arts and crafts, that sort of thing), and he generally has a pretty good day. He's pretty happy most of the time, but his life is limited. He's generally happy within himself.

People have a stereotype in their heads, often – and I did too – of what group homes are like, and what services are like for adults with disabilities, autism in particular. But if you have a child who's in this so-called lower-functioning area, or more classic autism, it really helps to look at some of these programs. You'll find they're not what you think, that they're a lot nice than what you think, and that will kind of help you as you plan for the future. These services are being developed more in most places, and certainly a lot remains do be done. There are not enough services for adults with autism, so I'd encourage people to get involved with your local and national autism organizations, and be – in that sense – part of the solution. There is a lot coming on now, and I think that will continue.

Likewise, there is a lot of politics to this, as we talked about earlier. In many states there are proposals to extend insurance coverage so they cover therapies our kids need. See what's going on in your states; get involved, see the candidates' positions, talk to them and see what's involved. These are all ways to plan for the future and make it a good future for our kids.

That's the way I'd look at this – whether your child has classic autism, Asperger's, high-functioning autism, or PDD-NOS. I'll throw in one more thing about the NOS: it means *not otherwise specified*, but I tell people to think about that as *not all the symptoms*. Every category in the diagnostic and statistical manual – depression or anxiety – they all have an NOS character at the end, within the classification, and it means having not all of the symptoms, but enough symptoms to consider this diagnosis. Generally, that's a good way to understand it – it's part of the autism spectrum, but not all of the symptoms that would qualify it to be classic autism. High-functioning autism is actually not a category, but we use it otherwise.

Ernest: A few more questions have come in here. One person wanted to know what your website address was, again.

Dr. Naseef: No spaces: *AlternativeChoices.com*.

Ernest: Okay. One other person asked about the title of the book, I believe it was *Grown-up Marriage*, and wanted to know the author's name.

Dr. Naseef: Judith Viorst. It's in paperback, around ten dollars.

Ernest: We have one question here from Victoria, Texas: "With all the emotions a parent feels when receiving an autism diagnosis for your child, how do you stay on the same page as your spouse and maintain a unified front?"

Dr. Naseef: This is the kind of thing we've been talking about all night. In some ways, I'd say let it go. You're two different people and are not always on the same page. If you let that go, you'll start to find your common ground. Try to find it simply. By that, I mean this is your kid – I'm sure you both love him or him – and do your best to help them. Do your best to talk openly and openly. Tell your spouse what they're doing right. Ask in a specific way for the help you need. This will help you feel together. I think that's what people mean by "on the same page".

You're never going to think and feel the same way at every moment, but how can you feel more together in it? I think a lot of that is the openness, the honest. Women want to talk about this more, men don't. I tried to give some tips for that. There's some of that in my book. You can certainly write to me, and I'll write more about this on my newsletter. Try to view it like a process that you're both going at, at different rates and from different perspectives.

Be patient with each other – compassionate and understanding – and often, men are a little slower on the uptake with these things. We really want to fix it, we really want to keep our families safe, and this is something we're powerless over. Not that women aren't powerless over this – we all are. But what we have power over – and I think this is one of the lessons of autism – we don't have the power to cure it, fix it or make it go away, but we do have power over how we relate to our child and how we relate to our family. If we focus in there, it's going to work out better. It's just going to work out better.

Ernest: I have another question from New York. They ask, "How does Aperger's and PDD-NOS differ? My son was diagnosed with mild PDD-NOS but seems to be going more towards Asperger's."

Dr. Naseef: That well might be true. PDD-NOS means not having all the symptoms required for autism. Asperger's further means spontaneous and age-appropriate speech and language, with average or above intelligence. The primary defecit in Asperger's is social skill – not speech and language or intelligence and cognitive. So, to some extent it doesn't matter, because what you always want to look at is "where is my child now, what does he or she need to advance?" So, in that way, if your child is getting good services and learning, you really don't need to get so hung up on the label: it's all autism spectrum.

Kids and adults grown and develop, and actually, at times, become less symptomatic. Your child may have been PDD-NOS, maybe closer to Asperger's now… you could, if you want, certainly have a full diagnostic work up with specialists, and it can be measured through observational testing, but it's not something, obviously, detected by bloodwork – it's behaviour and observation. Two professionals could come up with different opinions, but I would try not to get hung up on this and just focus on what your kid needs.

Ernest: We have another question – they want to know how to get on your mailing list. I believe they go to your website, maybe you could elaborate?

Dr. Naseef: Go to the websites, click on the button that says *Special Families*, and down at the bottom there's a box that says *Sign up for our Newsletter* – you can just put in your email address and you'll get the next newsletter which I'll be doing in the next few days.

Ernest: Great. We have a really great question here from Queens, New York. Her first question is, "What services do you find work best over the years for a child with autism?" Secondly, "What are your views on the brushing therapy?" and finally, "How do we get respite care?"

Dr. Naseef: First of all, it varies. Each child has an individual profile, but in general, kids with autism need speech and language therapy, many need occupational therapy (and that's where the brushing comes in) and they need special education services, behavioural therapies. But it's sort of a menu of things, like a Chinese restaurant menu, that have to be adapted based on the level of the child and the specific symptoms your child has. So, hopefully, you have a professional team of people in your child's school, or outside private people who are giving their input, and you're putting together a therapy which works best. One of the problems parents run into are, they go to specialists who all recommend what they do – that can be a problem because everybody is selling their services. The way you evaluate it is to see what is helping your child, and just evolve your child's program that way. The general menu.

Now, in terms of the brushing therapy, that's part of occupational therapy, and those things are really helpful. Again, you'd want a good occupational therapist to evaluate your child and recommend what kinds of sensory activities would be helpful. Brushing is one of many. Brushing might not be what your kid needs – they might need deep pressure, desensitization to certain sounds. A book you might want to look at is *The Out-of-sync Child* which talks about sensory problems and what can be done about them. But you want someone to do a good evaluation and recommend specifics to help your child.

Respite care – actually, I have a link on my website is: *Autism-PDD.net*. There is a link on there about respite care. There's a national respite locator site. I'm looking it up right now. You know, it varies by states. This is a national website and it helps you find local respite care – it's called *ArchRespite.org*. There was, about a year ago, some federal legislation and funding to help develop respite care through the country. It's not easy to come by. There are a lot of sort of do-it-yourself approaches, such as taking turns with other families. If you can't find these services available, I'd say don't give up. People are doing this through their churches, or community organizations, that sort of thing – as well as through social services. But the website I gave you – *ArchRespite.org* – is a good one.

Ernest: Okay. I have an interesting question here from a woman in Little Rock, Arkansas, I imagine. It is, "Since it isn't a good thing to apologize for your child being autistic, what is a good way to let a stranger in public know that your child has autism while your child is running up to them, pulling their clothes and trying to show them their favourite toy?"

Dr. Naseef: The Autism Society of America, for many years, has had these little cards about the size of business cards which give a short explanation of autism. A lot of people will carry these with them and give them out in such a situation. It really depends on what you're comfortable with, but that's one way that parents have been dealing with this for a good while. I think they're still available through the Autism Society of America.

Ernest: Let's see. I guess we're getting pretty close to the last five minutes now. Another person asks "What's the name of your website again? Sorry about this."

Dr. Naseef: *AlternativeChoices.com* – and go to the *Special Families* button, and at the bottom of that page, you can sign up for the newsletter – just put your email in the box.

Ernest: We have one question here again: "What about alternative treatments? Have any been successful, and why do insurance companies not cover any of these?"

Dr. Naseef: Well, they don't cover an awful lot of things, not just alternative treatments. Oh – I also see you can also get my newsletter on my home page – just put in your email, click *join* and you're on. Here's the thing – you'll want to put together a good basic program involving education and the basic therapies: speech, OT, behavioural therapy. Beyond that, people may want to try alternative therapies. Not just the reason that insurance companies don't cover them, but on many of them there's scarce data of effectiveness. Just anecdotal reports, like "so-and-so gave these vitamins to their kid and they started talking" as opposed to a scientific study. So, many of these things don't have scientific evidence to back them up.

It's not just why insurance companies don't pay for them, but it's also why they're not highly recommended. That's not to say some of these things might not help some children – I think the important thing is to do what makes sense for you. Get a good basic program going with education and basic therapies, and then, based on how your child learns, look at what's out there and see if there's something worth trying. That's reasonable, but be careful in terms of what's the side effects, and what's the evidence. A lot of parents feed desperate, and they want to do everything, and they want a cure if they can get it. But look at what the evidence is, and look at what the possible side effects are. Sometimes they're serious.

Ernest: Dr. Robert Naseef, I want to say thank you. Thank you so much for taking the time to answer our questions. I wish there were more, but I guess it's a slow Wednesday for a lot of people. We had a total of 89 questions and comments that came in over the time you spoke. I want to say, you've obviously helped strengthen a lot of marriages here; people asked a lot of questions about that. You've also answers a lot of questions about treatment which I think people are going to find helpful. So I want to thank you so much for your time, and I want to say, for those of you that are still on the line – as you know, we do these calls for free. You know you can call in and listen as long as you want, and ask as many questions as you want. We need to know what you think. To do that, there should be a link at the bottom right-hand corner of the page, that has a link: *give us your testimonial*. I'd love to hear it. For those who would like to give me a verbal testimonial, that is on the phone, I'd like to ask you to call a number and leave a message for me because I'd like to know what you think, and what you'd like to see talked about next time. What you liked about the call, and would like to see differently in another call.

That number is 1-877-211-0212. I want to know what you think; share with me your comments and whether you'd find this useful for friends or other people who have children on the spectrum. We'd love to hear from you. When you get to that number, just press number 1, and leave a voicemail for me; I'd love to hear it.

So once again, I want to say thank you. Thanks for attending.

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