

**“Women’s View Radio” interview, January 10, 2012 (Louise Gillespie & Deborah Bradley)**

<http://www.blogtalkradio.com/gillespie/2012/01/10/womens-view-radio-stephen-gallup>

**Louise:** Welcome to Women’s View Radio! And we are back today, it’s the second big show of the new year. And we’re talking today, we have a wonderful author on who has a book that is caring and loving, and his name is Steve Gallup. We have the book of the year, if it was mine to say. It is something that is near and dear to my heart, because it is very hard to get people to understand this disorder. OK, we have Stephen Gallup. The book is *What About the Boy? A Father’s Pledge to His Disabled Son*. Welcome to the show, Stephen?

**Steve:** Thank you so much for having me on. Good morning.

**Louise:** Oh, thank *you* so much for writing the book. As I was saying to you in our little host room there, I have not read a book that went about autism, autism spectrum, other developmental disabilities this way. And what I loved about it was I could feel your mind and your heart working at the same time. It’s a very wonderful and caring book. Um, kind of give everybody a little background.

**Steve:** Um, OK. Let me start with a question, a rhetorical question. It’s not meant to put you on the spot. What would you do if you had a little baby who was obviously in distress, every day, and who wasn’t achieving the usual developmental milestones, such as crawling? Oh, and the doctors weren’t helping, either. The book I wrote is a memoir that shows what our family did in that situation. Over a period of the first year and a half of his life, his mother and I were just frantic with worry because we could see—anyone could see—that something was just terribly wrong. And we weren’t getting—I mean, he didn’t have a diagnosis. Nothing was being done to help him. And I had begun with perhaps an exaggerated level of respect for physicians and medical professionals. And so I had no doubt in my mind that they were the ones who were gonna help us. And it turns out they didn’t. So, we were basically thrown upon our own resources, to do what we could. And as a result—well, I hope my book is not viewed as a really sad story, because we helped him dramatically. He achieved very important quality-of-life improvements, as a result of the interventions that we endeavored to provide.

**Louise:** In the legislature where I worked, I tried desperately to get them to understand what autism, what—not that we really *can* understand, because I don’t think anyone really, truly understands. Nor do they understand the heartache. Autism, I have it somewhere in my records, affects between two to six children out of every one thousand in the U.S., currently. OK. We have ever-growing evidence that this is real, increasing, and it’s getting worse, every day, for families and children. There’s more than one *kind* of autism, there’s more than one *level* of autism. That’s why it’s called a spectrum, Asperger’s being one of the most aggressive and most pervasive. Could we kind of go over how you got a diagnosis?

**Steve:** OK, well, autism makes a handy label in my son’s case. He got that diagnosis—actually, it was expressed as an *opinion*, of a neurologist. He said, ‘My opinion is that he has autism.’ This was when he was seven years old. But that opinion was previously discounted by other physicians and has subsequently also been disputed. Not that another specific diagnosis has ever been given. The most probable explanation for what he has is some sort of genetic error that occurred prior to birth. And it expresses itself in terms of some symptoms that resemble autism and maybe indeed falls within the spectrum, as you put it. You know, the figure that you gave is *very* conservative. A more common one is 1 in 110, and even that perhaps is outdated. I’ve heard of a study that gives the rate as up to 30%.

**Louise:** That was a year ago, the one I'm giving.

**Steve:** The Korean study, yes.

**Louise:** Well, I think it's even greater. The different studies, over the last ten years, on autism spectrum, OK, pinpoint the fact that you have more than one—the two greatest things that are possible have something to do with a level of toxicity, that's one, and the other having very much to do with birth defects, very similar to Down syndrome, that somehow interact with—when we say autism—it appears to be a multitude of things that happen or go wrong. Either way, they're not treating it. And one of the biggest things is: We always talk about what we spend on people, children, this, that, whatever. If you do not socialize children with autism, autism spectrum, and other developmental disabilities, and you do not help them at the lower end, it's really going to cause trouble at the upper end, later. Besides that, it's the loss of a life, for society.

**Steve:** Absolutely! Absolutely, you are so right.

**Louise:** So, I love your book. Try and give everybody a little track of where it all started and why you decided to, you know, put it down in print.

**Steve:** Well, when I started writing, I initially set pen to paper just as a means of emotional release, I suppose, just to try and sort things out. I was so confused by the events that were taking place. Back then, I had *no* thought of seeing it published! Turning those early notes into the book that finally saw the light of day was a very slow process. First of all, I had to recognize that what I had written was essentially a memoir. And memoir often tends to be a type of writing in which you contrast the point of view you had at the time you were living out that experience, vs your present-day perspective. And there *has* been some evolution in my thinking about this over time, and the book shows that change. So I decided—at some point, I'm not sure when—that this merited publication because it's essentially a story of chasing an objective, a very important objective, in the absence of dependable guideposts. Which I would say is something that I think a lot of people can relate to, including folks who've had other challenges, very different from mine.

**Louise:** You know what I love? In reading your book, it is a chronological—*oh, I'm trying to do this, and I know I have to do this*, and then we feel the pain that you had to go through on those steps. At one point, in fact it's on page 121, where the subject is miles of creeping, one day at a time. You can't keep the stroller, you have to carry him, you can't use a wheelchair because that would not promote his mobility. You were trying every which way to find the right way around the problem. At the same time, we feel the pain of a father who says it's so hard to watch him suffer. If anyone wants this book—where can they get the book? That's number one. I know you have a website. But you need to let everybody know about this. I can clearly see this being the winning book of the year, because I felt everything you were going through, when I read it.

**Deborah:** I'd like to say that I haven't had a chance to read the book. I'm sorry for that, but I *have* read your website and everything. And I want to read your book, because I have a couple family members that are autistic. However, the parents and the doctors—either the doctors don't say they have it or the parents choose to ignore it. But how do you go about telling someone—without *telling* them—that they need to become a little more involved in trying to help their child?

**Steve:** OK, I have been in that situation with other folks, and that's dicey. I'm just guessing here, but I suspect that quite often those folks know more than you think they know. In our case, early on, we built a wall around our family. We were trying to prevent the outside world—we didn't want to acknowledge this. I'm not talking about with doctors. We *wanted* the doctors involved. But in terms of other people, we wanted to get this resolved before we presented our child to the world, in a way. So, my first point is that they might very well believe that there is a problem and they just don't want to acknowledge it. *Perhaps* they're in denial. And perhaps they're just trying to deal with it on their own. But yes, maybe they *do* need help, and that's tricky—.

**Deborah:** I would like to get your book so that I can read it so that if I find that it's informational I can give it to them without them—.

**Steve:** My book is not meant to be instructional. I don't want to—.

**Deborah:** No, but it might give them the—the light bulb might go off.

**Steve:** It's a story that they might relate to. They might recognize.

**Deborah:** Right.

**Steve:** I should also mention that they might find that what we did was an example of what you should *not* do. In many regards, I think, we took steps that were perhaps the wrong steps, in some cases. I mean, I'm not saying that everything we did was wrong, because we certainly helped our son—.

**Louise:** Hold on. We have a break coming. We'll be right back.

\* \* \*

**Louise:** We are back, Women's View Radio, and we are talking with Mr. Gallup. The book is *What About the Boy? A Father's Pledge to His Disabled Son*. And one of the things we were talking about before the break: This isn't a book that says *This is what you do*. This is a book saying *This is what I went through. This is what my child went through. And this is how we went about trying to find a way to fix it*. That doesn't mean it's the right way, but I can feel everything you did here. And I believe this should be one of the number one books of the year.

**Steve:** It's very kind of you to say that. To finish the thought I was pursuing before the break, *What About the Boy?* is a case study in making choices and living with consequences. Consequences can be good or bad. I'm convinced that our decision to go—well, let's say “off the grid,” so to speak, in terms of parting company from medical providers who were not trying to help our son, and instead finding a course of action that was aimed at a worthy objective—this decision had good consequences. First of all, the prevailing attitude in our house became extremely upbeat. Optimism reigned! And optimism reigned even more strongly when our son began making progress, developmentally. There were other families we knew who chose differently. They accepted the premise that nothing could be done for their kids, in terms of improving their abilities. And it was obvious to us that they were not happy campers. And so we did not want to be like them. But on the other hand there were other consequences of our decision that weren't so nice. It's *not* good to be alienated from medical providers. It's *not* good to impoverish yourself, or to make yourself sick in a long-term pursuit of an elusive goal. Because a thing like this *is*

long-term. It's not something you're gonna resolve in a month or two. Or a year. In some ways, the story I tell is a cautionary tale. As I said a moment ago, I try to point out that it's not instructional. It's a story. And I think it's safe to say it shows that we did not make all the right choices.

**Louise:** Nobody does.

**Steve:** That's true! Taking steps—.

**Louise:** If you did, if you knew all about it, you'd do one thing, it would get resolved, and that's not the way it goes. I love the way you were talking about options, pursuing options. There's a study out there about amino acids, the building blocks of life. Giving all the amino acids may be a way to repair some of the damage. And maybe even giving that in utero would help prevent it. So there's so many things, and my fear is that someone might instead wait until it's too late. You said it's a cautionary tale. Yes, but you tried! You know what I mean? You tried. OK, the essential fatty acids help build brain function, the connectors, everything else. It says that developmental portion affects—whether it's hormonal, whatever, no one's really sure how those factors work, but it has shown to be beneficial. I have two people who are chiming in. I'd like to tell them to hold on. I've got a few more things to go over before we do. Can you give people your website?

**Steve:** Certainly. My book's blog is fatherspledge dot com. That's just one word, fatherspledge, with no apostrophe. And that has links to reviews that have appeared about the book. It's a blog that includes my musings that I put up from time to time, and it has a link to Amazon as well.

**Louise:** I'm telling you, anybody, if you have a person in your family—not necessarily with autism, not necessarily with any disorder—. You show *so* much of yourself, and your heart, in this book. And of the way you are chronologically trying to find an answer. I think I love that more than anything else. I can see the difference between what your heart felt for your child and your mind trying to find a reason. [Laughing] Does that make sense?

**Steve:** Well, yes it does. And it's interesting that you would see it that way. I was in a critique group, with other writers, when I was trying to get this into shape. And a lot of them had issues, said I was so analytical, so technical. Um, and they had to get used to that. And they wanted me to tone it down and show some more emotion.

**Louise:** Well I think it does!

**Steve:** OK, good. I'm glad.

**Louise:** You see, the point is—I just got the book yesterday. Your publicist sent it out and somehow it got lost in the shuffle, and I literally got it at about three o'clock yesterday. And I didn't start reading it until—I guess it was about seven o'clock. And I read it until three o'clock. I went through it and tagged it, and Deb I'll give you the book so you can read it. Um, what I saw was a father trying to disconnect on the emotional end to find, you know, almost like a scientist: *This is what's happening. OK. And I'm going to deal with it in a scientific way. I'm going to find my way out using this times this equals that.* And then you run into a wall and say *That shouldn't have happened. It should have ended up this but instead it ended up that. OK, how do I fix this?* I see it differently, maybe as someone who's been around autism and a lot of people with developmental disabilities, I can see what you were trying to do. And it is

heartbreaking. It's heart warming. I see your heart in here. I see every breath you take, trying to see the best, scientific way out. *[Laughing]* Does that make sense?

**Steve:** Well, I tell you it's music to my ears that you understand it so well. The cover image is supposed to represent a maze. And a maze is really sort of a motif that goes through there—you know, being lost and taking one alleyway and finding it doesn't lead anywhere and then trying to backtrack. That's really what the experience was like for us.

**Louise:** And you were trying to say it and put the best face on it. I could see, over and over again, I could see the walls coming up, OK? And I see you trying to say *Wait a minute. THAT shouldn't have happened. That's not what I thought was going to happen!* And for everyone who has someone in their life, not necessarily a developmental disability but a disability in any way, whether it's emotional, because we have a lot of people who have problems psychologically or physically, what I see is a person trying to be—strong, in the face of this ultimate crime in the human condition.

**Steve:** Yes—people talk about us being strong, and I have always argued that I didn't see any particular strength in what we did. We just did what we felt that we *had* to do. And I always want to bring the point up that this is not specifically *us*. It's not about us, the parents, the adults. It's about the kid. Because it affects him, it affects the child, much more than it affects us. We're going to be gone some day but he's going to live with the consequences of what happens. And so we the adults have an obligation, I think, if we're going to bring a child into the world, to give him the best possible—to launch him in the best way. And so I was just doing what I thought had to be done.

**Louise:** The book is *What About the Boy? A Father's Pledge to His Disabled Son*. And we've got a break. We'll be right back.

\* \* \*

**Louise:** This is Women's View Radio and we are back, with Stephen Gallup. The book, *What About the Boy? A Father's Pledge to His Disabled Son*. We're got a few people backed up, so I'd like to get to them. Is that OK, Stephen?

**Steve:** Certainly.

**Louise:** OK, we have Janet in Tampa, Florida. She says, "Doctors can never say yes or no about my son. What can I do to move them along?"

**Steve:** OK. Janet needs to understand that if the doctors are not helping her son and she is confident that her son needs help, then she needs other doctors. That's a glib statement, but it's factual. I mean, the fact is that early intervention is critical for children. Just go ahead and Google that phrase, early intervention. You'll find that it's widely accepted that you get a better outcome if you take steps to get effective treatment early, rather than later. And there are doctors out there who will not do what's needed. I don't want to give reasons for them—I can think of some reasons—but it's easier just to push you back out the door, give you another appointment, and hope things get better on their own. But there *are* doctors, there *are* resources that can help you. You just need to find them. Now, there was a doctor in our experience, when we said, "We've got to have help on this, there's *got* to be something we can do," this doctor said, "Talk to other parents." I thought that was an abdication of the doctor's responsibility, but I suppose she

was trying to avoid going out on a limb and appearing to endorse something that she thought was sketchy. So she let us do the legwork ourselves. We did this back in the 1980s. That was prior to the Internet. Today, it's much easier to find things out. It's much easier to find doctors who are in this on *your* side, and you just need to do that. If that means leaving some other doctors behind, go ahead and do it.

**Louise:** Jilly in North Carolina. She says, "Where can I buy the book?"

**Steve:** Well, bless your heart. Any bookstore either has it or they can order it. Barnes and Noble in my town has it in the Family and Childcare section. I don't think that's necessarily the best place to put it, but at any rate that's where they display it. It's on Amazon. It's on various online sellers. It's not hard to get.

**Louise:** Chris in New Jersey says, "My son is getting increasingly harder to handle. He has outbursts that he doesn't understand. The school does not do anything to help him while he's there. What can I do? Do I need to move him out of school? I think he needs the socialization."

**Steve:** Hmm. Well, I can't speak specifically about that, not knowing her son, and of course I also am not qualified to hand out advice. But speaking generically, the school doesn't—I presume this is a mainstream school—they probably have no training or no background in dealing with something like this. The first thing is: Don't blame the child! The child is reacting to conditions that—it may be a sensory problem that's causing the input he gets from the world to be chaotic. Some children, for example, react to blinking of fluorescent lights in the classroom, just to pick an example. We don't even perceive these things, and it's driving the child mad. Or it could be a sound that—we hear it but more than likely we filter it out, because we know it's not significant. But some children have trouble ordering these perceptions and focusing on what's important. They become—they create a conduct problem, if you will, simply because they are unable to sort out all these inputs. So, as to what you should do—a developmentalist needs to go over the situation with you. And it's perhaps a painstaking process of eliminating factors and finding what is going to make things better. I hope medication is not the answer. For some people that is the answer, but it has side effects, and those are things to consider as well.

**Louise:** What are some valuable tips you can give for challenged parents, then?

**Steve:** Well, gosh, there are so many—. As I said, I'm not an authority. But having said that, sure, I could not have lived through this experience without drawing some conclusions. And the first one is that a child who's got problems such as this, first and foremost, is still a child. I know that sounds like a bromide, but like other well-worn bits of good advice—such as, you know, eat well, get enough sleep, and so on—it sounds familiar for a reason. And I know from experience that it's all too easy to forget the obvious stuff. All kids need to be treated as kids. What I'm recommending here comes most easily when you are dealing with an apple-cheeked youngster who says cute things, and gives you lots of great feedback. But on the other hand, a child who has problems that make him less than cuddly or responsive, that child may inspire enthusiasm on your part for finding professional help. And that's great. However, he also desperately needs to be told, right now, repeatedly, in every way, that he is loved and cherished. Kids who give you no eye contact, or who are rigid or combative—they need this reassurance at least as much as anyone else. So in addition to being an advocate for your child, you've gotta remember to be a daddy or a mommy. That's *one* tip.

**Louise:** OK, we have Alice “the world’s greatest mom ever,” she says. She texted this. She says “I’m not bragging. I just like myself.” She says, “I was very lucky. My daughter was not. Her son received a vaccination when he was a baby. Shortly after, he had a severe reaction to that vaccination, and we believe that vaccination is what brought on his disorder. Do you believe yours might be a vaccination issue, or was yours a different type?”

**Steve:** OK, speaking for myself or my son, *his* problems started before he ever saw a needle. He was disabled from the get-go. Having said that, I was paying attention when the vaccine controversy erupted. I guess it was in the mid-90s when it started to get traction. That’s also when the Internet took off, so maybe some correlation there. But I have always been sympathetic to the people who feel that vaccinations are a cause. It’s a possibility that vaccinations also played a part in making my son worse. I have reason to believe that there’s a genetic condition, inherited from my father, that makes people in my family vulnerable to the pertussis toxin in the DTP shot.

**Louise:** Oh yeah.

**Steve:** That’s based on research done by a doctor in Richmond, Virginia. But it’s speculation. I don’t know. But the fact is, because, in our experience, the physicians were stonewalling us and were not giving us good answers, they made us distrust them. And I never *wanted* to distrust them! I wanted them to be on my team. So, when I started hearing people with stories like Alice has just given us, about vaccinations, I’m inclined to believe that they’re right. And the fact that most doctors are poo-pooing that doesn’t impress me a whole lot. But this particular controversy is not central to my story, and I’m only sort of an onlooker.

**Louise:** I think there’s just—you *don’t know*.

**Steve:** I think as a society we’re too quick to come up with answers.

**Louise:** We’ve got Chris back from New Jersey. She says yes her son is in a public school. “Is there a better school for him?”

**Steve:** Probably. But I—oh, golly, there are some—.

**Louise:** [*Laughing*] That’s the subject of your next book, right?

**Steve:** We took our son Joseph out of school, out of public school, after his first year, after first grade. And we put him in what is called a “nonpublic school.” This was something—it’s like a private school but it’s paid for by the school district. And this involved a lot of butting of heads, in meetings and so forth. I’m not sure that—well, yes, it *was* necessary in his case because they were just not addressing his needs. He was in a room with such a huge range of kids. Some of them were ESL students. Some of them were wheelchairs. Some of them were *big*, hulking kids, bigger than the teacher, who frightened the teacher. We had to get him out of there. So, short answer to the question” What to do? There are yahoo groups, there’s one—I can’t think of the name of it now, but if you do a search, you can join these groups and you can post a question like that and you’ll find somebody in your state who can tell you what to do.

**Louise:** We’ll be right back with Women’s View Radio. [45:41]

\* \* \*

**Louise:** I just love those really old commercials.

**Steve:** I like that.

**Louise:** We have one. Well, we have several. Um, Desiree—

**Steve:** Hold on, Louise, could I follow up real quick?

**Louise:** Sure.

**Steve:** On Chris's question. She asked about what to do. During the break I looked up a couple resources. ambd at yahoo dot com is an autism discussion group. I forget exactly what that stands for. And also Schafer Autism Report is a subscription email thing. It costs \$35 a year. Schafer at sprynet dot com. Those are two resources that are active that I know of, and I think the first one in particular to get answers to questions such as the one Chris raised.

**Louise:** Desiree doesn't say where she's from. She asks, "Was it hard to make your story public?"

**Steve:** Yes, yes, writing memoir in general is hard. I'm quite familiar with what other people have gone through with theirs and have seen many people reading excerpts from their memoirs who end up breaking down and crying in the process. Yes, it was hard, but it was a good thing for me. It was healing. Number one, it helped me make sense out of a lot of things that had not made sense to me before. And as I think about it, I'm *still* reaching new insights now. I think the whole process is painful but I'm very glad that I did it.

**Louise:** We have a—this is a funny one and an interesting one. Deborah in Michigan says, "Hi to Deborah and hope you're keeping Louise in line. That's a joke."

**Deborah:** I'm trying!

**Louise:** OK, watch it. She says, "Mr. Gallup, while I have no one in my family who is adversely affected, how can I and others help families like you? We're all strong together. That's why I listen to Women's View." And she says, "That's a plug." Ha-ha.

**Steve:** [*Laughing*] I've never heard that question before and I'm glad to hear you ask how other people can help. Just being understanding is a very big step forward, because people in public, when they see someone acting strangely—wagging his fingers in front of his face, or not standing in line in the grocery store like he ought to—a little tolerance on their part goes a long way, because parents come in sometimes for a lot of unspoken criticism, that they feel. *They* don't want their kids to be creating a disturbance. If they know that the world is with them, as opposed to judging them or their child—I think mothers feel this especially. My wife suffered a lot at the thought that the world was not accepting her son. If you can let folks know that you're with them, emotionally, that gives them a lot. Thanks for asking the question.

**Louise:** Another one is Annette. She is outside New Orleans "in the sticks." She says, "There are no groups near me. Nothing. What can I do? My son needs help. He needs to be with others like himself, I think. Is that the right course?"

**Steve:** Is what the right course? I'm not sure I understood.



**Louise:** She thinks other children like her son need to be with him.

**Steve:** Oh. That's a subject of debate, whether or not you should put kids together. *I think that the primary source of help for the child is the parents. In other words, the parents need to be involved with helping him, or somebody but preferably the parents. As for being out in the sticks, the good thing about these days is you have the Internet. Anybody, anywhere can be just as close as your keyboard. You will not feel lonely if you can connect with them that way.*

**Louise:** It's so hard for any parent that has a child, when there's a learning disability or developmental disabilities or a disability of any kind. Or you have a child that's ill, a child that has a problem, emotionally or otherwise. I like what you said about mothers. I think you're right on that one. *My child can't develop—somehow, I've got something wrong as a mother and that's why he has the disorder.* A lot of women feel that way.

**Steve:** Oh yeah. I've written blog posts about that.

**Louise:** Yeah. And for the mothers out there, *that isn't so!* And far too often people do that. I have a lot of disability in my family. And so you think, *If that's there, it must be something you've done.* I'm one of six kids, and I have uncles and aunts who have six children and five children, seven children. And there may be one out of a group of seven, none out of a group of ten, two out of a group of sixteen. It's a crapshoot. You never know what's going to happen, whether genetically, environmentally, or both. OK, so we don't know. Spina bifida is a good example. You have so many children and maybe one of them has spina bifida, cerebral palsy, Down syndrome. I don't think anyone truly understands, nor do they know, but it's so difficult for mothers. Because they've given birth to a child with a disorder. Maybe that's something we can close with. What would you tell mothers out there

**Steve:** Oh, what a tall question you're hitting me with at the end here.

**Louise:** I'm sorry!

**Steve:** [*Laughing*] Um, it's a matter of putting things into perspective. I think having faith that when it's all over, when you're looking back, it's gonna make more sense that it does right now. I think that you're doing a disservice to everyone if you beat yourself up. The trouble is that telling someone that is not going to help, because this is an emotional reaction. I think my wife understood this intellectually, just fine, but that didn't make any difference because she *still* blamed herself. She had—this is based on issues going back before I ever knew her. Someone told her that she would not make a good mother. And she wanted to prove to herself that she *could* be a good mother. And it's just so heartbreaking when something happens and you try to prove that, for your *own* satisfaction—you're not trying to convince anyone else. Um—I'm rambling here, because I don't know what to say to somebody except: Try to get past the pain, and try to remember to love your child. Because your child is *still* lovable.

**Louise:** We're going to have to have you back on. We're done for today, but you left a lot of people hanging. So, remember to get *What About the Boy? A Father's Pledge to His Disabled Son*, Stephen Gallup. God bless you and keep you and we'll see you guys tomorrow.

